

**Positive Sex and Risk:**  
**Social and Sexual Negotiation with HIV**

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This thesis is dedicated to the memory of two friends, Roy Tippet and Barry Hayden, who privately revealed aspects of life with HIV. They died of AIDS related conditions in a less enlightened time. My hope is that this work will enable others an insight into life today with HIV so that the issues Roy and Barry died alone with can be arrested. How far have we come?

## Abstract

Modern society has been termed a 'risk-society', one in which risks are produced and become incorporated as parts of our daily lives. The Human Immunodeficiency Virus (HIV) is one risk that can be identified and centred within the body of the HIV positive person, resulting in a 'self-management' role for that person. Increasing regulation and control over the HIV 'positive body' paradoxically increases the risks for the positive man and their sexual partner. This thesis explores how ten HIV positive men negotiate their social and sexual practices in the context of a risk society.

Semi-structured interviews, within a paradigm of qualitative research, were held with ten HIV positive men during May 1999. A thematic analysis illuminated a series of social tensions that exist for these men. A sociology of risk provided a theoretical framework in the analysis of these tensions. This thesis argues that risk can be individualised when identified in our society. The HIV positive body is localised as 'risk' and as such becomes a focus of increasing regulation and control. Such control places the positive person in new situations of risk.

This study adds to a growing mass of social research into the living experiences of New Zealanders living with HIV, and an increasing international literature in the sociology of risk. Social closure, social pressure and living with uncertainty are tensions that highlight the use of a sociological perspective of risk in HIV social research. An inclusive approach to the social and biomedical issues faced by HIV positive people is essential. A series of social tensions operate alongside of the bio-medical treatment discourse for these ten HIV positive men today. Further areas of research are suggested.

## Abbreviations Index

ACT	AIDS Committee of Toronto
AIDS	Acquired Immune Deficiency Syndrome
Express	New Zealand's newspaper of gay expression
HIV	Human Immunodeficiency Virus
HIV negative	Someone who has not contracted HIV
HIV positive	Someone who has contracted HIV
Hui	Maori gathering and meeting (formal)
Maori	Tanagta Whenua (first peoples) of New Zealand
MSM	Men who have sex with men
NZAF	New Zealand AIDS Foundation
Pakeha	Those other than Maori (eg of European ancestry)
SMASH	Sydney men and sexual health study
Sydney Star Observer	Weekly gay community newspaper - Sydney
Whanau	Maori cultural understanding of family unit
Whakapapa	Genealogy
WINZ	Work and Income New Zealand

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## **Chapter 1**

### **Introduction**

Contemporary society has been termed a 'risk society' (Beck 1992) and one in which risks are produced because of industrial and technological advancements. A risk society is also global and the risks can be unnoticed and undetectable. A risk society is one in which risks are inevitable and a consequence of increasing deregulation of the market place. The Human Immunodeficiency Virus (HIV) will be used in this thesis to argue that a risk society is one in which increasing controls and regulations, designed to manage risk, may paradoxically result in an increase of risk for a group of ten men who live with HIV in New Zealand.

This chapter sets a context for the thesis argument that risk in New Zealand's neo-liberalist society has become individualised as we are encouraged to monitor health and self-regulate behaviour (Castel 1991; Scott & Freeman 1995). Firstly, the neo-liberal context of New Zealand is discussed to illuminate a context for introducing Beck's (1992) 'risk-society'. Health policy and understandings of risk can be situated within this paradigm. Secondly, there are two antecedents to this research and they are outlined here. The first is a discussion of my personal experiences with HIV and AIDS. Following this I will discuss the recent arrests of four HIV positive men in New Zealand between April and July of 1999. The chapter concludes with an outline of the thesis chapters.

### Situating HIV in a Local Context

The Human Immunodeficiency Virus (HIV) replicates and leads to immune system damage and progression to an Acquired Immune Deficiency Syndrome (AIDS) diagnosis. However, while living with HIV it is possible to remain asymptomatic (no physical symptoms). Being HIV positive means to have contracted the virus that can cause AIDS. Being HIV negative means to not have contracted the virus. Being HIV positive and identifying as a gay man may mean the gay community is a possible site of support. Being HIV positive and a non-gay identifying man who has sex with men will produce another set of social experiences.

Defining HIV is also related to local context. The number of people in New Zealand notified with AIDS, as at June 30 1999, was 681. Of these 647 are male and 34 female (AIDS New Zealand 1999b). The number of known HIV positive people in New Zealand at the same period is 1371 and of these 1199 are male and 153 female. AIDS New Zealand (1999b, p1) notes that "The number of people notified with AIDS in the second quarter of 1999 was the lowest quarterly figure since 1986." AIDS New Zealand acknowledges that these figures are estimates as some people will be living with HIV and not be aware of their HIV status. During 1998 29.5% of those tested for HIV were Pakeha, 3.8% were Maori and 1.0% identified as Pacific Island peoples. Forty percent of those tested in 1998 were outside these three ethnic groups and 5.7% did not identify an ethnicity, or this information is still to be collated. These statistics show an increasing gap between those with HIV and those with AIDS, or those known to have died (see appendix 1). This raises two issues for the monitoring of AIDS in New Zealand. Firstly, HIV is not a notifiable condition in New Zealand at this time and secondly, the behaviour as well as the virus is under increasing surveillance. In 1999 there are more people living in New Zealand with HIV than in any other time (AIDS New Zealand 1999a). This context of living with HIV has replaced the experience of 'dying from AIDS' for many people with the

virus. However, the recent treatment advances available in New Zealand mean new sets of social practices and risks occur for people living with HIV today.

[T]here needs to be widespread testing of people at risk and use of treatments among those infected. An important factor here is that people are particularly infectious soon after HIV infection is acquired which may be before the infection is diagnosed. Secondly, with treatment infected people will live longer, and remain at risk of transmitting HIV longer. In addition, the transmission of strains of HIV resistant to multiple anti-retroviral agents is now well documented (AIDS New Zealand 1999b).

The decreased incidence of AIDS among people with HIV means that AIDS monitoring is less useful than ever in understanding the epidemic of HIV. Therefore relatively more emphasis needs to be given to surveillance of HIV infection. This needs to incorporate both information on the pattern of diagnosed HIV infection and patterns of testing, and also prevalence studies in particular groups. In addition there needs to be monitoring of behaviours known to spread the virus (AIDS New Zealand 1999b).

While a significant drop in the number of AIDS diagnoses has been noted (AIDS New Zealand Issue 1999b) the introduction of anti-retroviral treatments provide hope for living longer while introducing a new set of social issues to consider. However, as the above statement indicates, there is a call for the monitoring of behaviours defined as having a 'risk' of transmission. This position is taken as a result of bio-technical advancements in the treatment of HIV and AIDS.

Protease Inhibitor Therapy has been developed and is available in New Zealand. The use of these combination anti-retroviral drugs can suppress HIV replication to below detectable levels, in some people. Combinations of drugs are used to delay disease progression (Kempf 1998). This combination therapy is scheduled and designed for the individual patient. Having undetectable viral levels still means the person lives with HIV.

The new 'cocktail' of medication is proving successful for some and debilitating for others. Regimens of up to 40 pills each day mean compliance may be an issue. Managing this number of medications presents issues for people living with HIV. Social research can assist in informing an understanding of what living with HIV today may mean. It will be used here to highlight how a risk-society (Beck 1992) produces risks that can be seen as cleavages in contemporary society.

This research is not speaking of a generic HIV experience. Each man in this study has a set of understandings and perspectives about their life. The experience for an elderly retired pakeha man is different to that of a young Maori male who is not whanau (family) connected. As Race (1999, p19) states:

The experience of a gay man with HIV in Darlinghurst is entirely different to the experience of a Thai mother with HIV – so different, in fact, that they may as well have completely different viruses in their bodies.

Race (1999) is juxtaposing Darlinghurst, an inner Sydney area where many gay and lesbian people live, with Thailand. In so doing the comparisons include rural-urban, gender, social roles, sexual identity and access to support. Christchurch is again different to each of Race's (1999) locations with a specific ethnic mix, largely Pakeha, that is of European ancestry. Within the HIV positive community there are gays, heterosexuals, intravenous drug users (historical and current), men, women and children from a variety of backgrounds living within a society that has embraced restructuring and economic market reform in many sectors over the last two decades.

The context of HIV is situated within recent social and economic reform. From 1991 the then National Government began implementing a restructuring of the health sector. The reforms in health occurred in a context of political, economic and social change for New Zealand. A market approach toward health and other areas of society occurred in other Western nations at this time (Fougere 1994). Managed

competition became central to the health system. It was argued that productivity would be increased by dividing service provision and funding and, thus, fostering competition. One outcome from this approach was the competing of health insurance companies for clients in an open market. The selection of low-risk customers meant the state health system became the system for high-risk people.

Such change occurs within a neo-liberalist system, one New Zealand adopted in 1984 (Cheyne et al 1998). The principles of neo-liberalism are the encouragement of individuals to make their own choices, removing impediments to a market economy, a focus on cost-effectiveness and a recognition that the market is a complex system for buyers and sellers (Cheyne et al 1998). The argument follows, then, that economic growth would create employment. State intervention exists within a neo-liberal framework as an enforcer of law and order. The state is therefore a port of last call, operating to assist when the private sector fails or is unable to provide such growth.

Individual freedom, as a central tenant to a neo-liberalist government, is also what Beck (1992) argues is an outcome of the 'risk society'. He believes that in modern society the production of goods and services, coupled with an increasing technologically based society, produces risk; the decisive feature of modern life, is the way individuals incorporate their understandings of life into their view of the world (Beck 1992). A reflexive society is a risk society because the outcome of a decision or choice may result in a wrong or unwelcomed outcome; a 'risk biography' is reflexive (Beck 1992). The concept of reflexivity can also be considered in terms of antecedent factors.

### Antecedents

Firstly, I will outline the ways in which this research has interested me as a gay man, and as a social worker within the HIV/AIDS field. HIV has been an issue of interest and loss in my life, something I consider reflexively. As a 34-year-old gay identified man HIV has been something I am aware of and an issue that has intersected my own life. From 1983, when I first heard about the virus 'killing gay men in New York', HIV has continually shifted and developed, both as a virus and as a socio-cultural experience. This virus has infected people I know and continues to be transmitted. To date my HIV status is negative, making me something of an outsider to those under study. My employment at the New Zealand AIDS Foundation allows a consideration of what Bolton (1995) calls the line between the personal and professional. Before a professional role in HIV work I had and indeed retain a personal role.

I lived in London and Sydney through the 1980s. Stories of the 'gay cancer' and 'gay plague' appeared in newspapers from 1982 onward. In the gay communities survival stories provided a counter-discourse to the popular media portrayal of death and dying. While people were contracting HIV the gay communities in London and Sydney mobilised around HIV and AIDS. From within gay communities in New Zealand people worked to create a cultural shift toward safe sex from 1983 (Lindberg et al 1996). While many gay identified men adopted and promoted safe sex practice the number of infections continued to rise. Two recent events, the death of a close friend in Sydney and the arrests of HIV positive men in Christchurch, highlight the importance of this current study.

Barry, a close friend of mine, died alone in Sydney in 1996. As he was unable to tell his family and many of his friends about his condition, his death symbolically represents the gap in understanding around living with HIV. Barry told me he felt people would judge him because gay men had had time to learn about HIV. He

considered his friends, mostly gay men connected with Sydney's gay community, to be unsupportive. As one of two people he told, I was concerned that the friendships and community of gay men we knew were seen as such limited support. Barry found difficulty in disclosing his HIV status to his family and friends. This personal decision by Barry rested with him. However, at times the decision to disclose one's HIV status is not left to the individual.

The second antecedent for this research is my professional role as a social worker in the HIV/AIDS field. In late April 1999 two men were questioned by the police and subsequently charged with making a criminal nuisance for not disclosing their HIV positive status prior to unprotected sexual intercourse. The arrests drew heavy media attention as this was the first time a New Zealand citizen had been charged with this offence (Christchurch Press 29 April, p1). Two weeks prior to this Immigration Minister Tuariki Delamere called for the testing of all immigrants for HIV. This issue also drew media attention (Christchurch Press 14 April, p9). The media coverage in both situations employed 'risk' as a metaphor and one that operates to situate the person with HIV, in this case immigrants and sexually active HIV positive people, as the potential infector. The following headlines appeared at this time:

Immigrants with HIV too big a risk - Delamere (Christchurch Press April 14, p9)

Police warn of Chch men with HIV (Christchurch Press April 29, p1)

Deluge of calls over HIV - Infected men prompt scare (Christchurch Press April 30, p1)

HIV man had sex every day (Sunday Star Times May 2, pA4)

Police make new arrest for HIV sex (Christchurch Press May 17, p1)

By July, four HIV positive men had been charged with a criminal nuisance. Three men entered guilty pleas while the first arrested awaits trial by jury. Three men lived in Christchurch and one in Auckland. The later two men received jail terms while the first two remain held under the 1956 Health Act. This legislation empowers the Medical Officer of Health to detain any one whom is knowingly 'spreading' a range of diseases, including AIDS (HIV is not included in this legislation). Detention and the removal of the men from the community, through this use of the Health Act (1956), prevent the virus from infecting others. Dr Brieseman, Medical Officer of Health, commented that the men could be isolated under Section 79 of the Act and it was reported that "he was confident sufficient measures were in place to ensure the disease would not spread" (Christchurch Press May 21, p2). This comment sends a message to other people living with HIV that society has a very clear position on this matter. The Christchurch Press (July 28, p13) reported, in an article entitled "Duty behind HIV publicity", that the

Police had a social duty and obligation to make information about an HIV-positive man public, a constable [Mr Shaw] said in evidence to the Christchurch District Court...

Mr Shaw said police had an area of Hagley Park under surveillance before [the] arrest...Mr Shaw said the area was known to police as a place people went for anonymous sexual encounters, or "beat sex" as it was known.

In his summing up of sentencing one of the men Judge Michael Green is reported as saying the 'court had to impose a deterrent sentence to alert others of the importance of their responsibilities to their sexual partners' (Christchurch Press August 14, p2). Here Judge Green's comments support the earlier police position of making this issue public as the community has a 'right' to know.

The arrests and continued media attention had a dual outcome; firstly, the detainment of the HIV positive men and, secondly, locating the source of the virus within the body of 'an offender'. The detainment of these men removes the risk of infection thus guarantees the protection of others. The media report that the police are aware of the



locations of sexual encounters and have a 'duty' to the public to inform them of the risks occurring in this context.

Risk then is detained, isolated and controlled. Beck (1992) would argue this is an outcome of our 'risk-society' as managing risks is a feature of our time. For Beck (1992) a risk society is one of anxiety around the unknown. In the arrests and detainment of HIV positive people this year the risk is identified and centred; that is, the risk remains (through control) within the body of the infected man. Beck's (1992) theory that modern society is one in which risks are produced with industry and technology is central to this thesis which will show the impact a risk society has on ten HIV positive sexually active men. As the above example demonstrates, society has expectations around the actions of HIV positive people. The spokes-people for society quoted here are the police and a presiding Judge. Using a risk lens this thesis will show that risks can paradoxically be increased through increasing external controls and regulations.

The argument here is that risk is a feature of modern societies (Beck 1992; Giddens 1990). As such the changing relationships between social structures and individuals result in risk becoming individualised, something to be self-regulated. Such self-regulation of risk is a feature in the lives of the ten HIV positive men featured in this thesis. However, increasing external controls and regulations on HIV positive people paradoxically result in an increase of risks for these HIV positive men and their sexual partners.

### Outline of the Thesis Chapters

The study is divided into six chapters. A review of the literature follows this introduction. Chapter Two introduces the sociology of risk as a framework for considering the issues confronting the ten men today. Through a qualitative approach ten men, who are HIV positive and have sex with men, were interviewed in May of

1999. These men live in Christchurch, which is New Zealand's third largest city and has a population of approximately 322,000 (Adams 1999). Chapter Three outlines the methodological approach taken in this research. Using a qualitative approach semi-structured interviews were held with the HIV positive men. The interviews were transcribed verbatim. This study in no way sets out to state the experiences for all HIV positive people but places the lives of these ten men into a local context of living in a regional city in New Zealand.

The research findings are divided into the next two chapters. Chapter Four discusses the context of risk for these men. This context includes the social structures the men engage with. The relationships these men have with areas of society are discussed here. Through a reflexive engagement the men gain a sense of how others view HIV. This then affects these sets of relationships. Chapter Five argues that the relationships these men have with these institutions produce a range of responses and management strategies. The sets of social relations they engage in highlights how they manage new emergent sets of risks. Results indicate that the HIV positive men engage in risk management through their social and sexual negotiations. Paradoxically, the management of individual risk for themselves may place their sexual partners at risk of HIV infection. Chapter Six, a summary and discussion chapter, considers the significant findings of the study and concludes the thesis.

This research adds to existing quantitative research available in New Zealand and allows an insight into this group of people with HIV. The men shared their experiences as contemporary social and sexual people. This means that these men are developing a new set of management practices in a reflexive way, within a context where HIV is regarded as an individual issue. Alongside bio-medical treatment advancements there are a series of social tensions for these men. They are living with uncertainty, social closure and social pressures. This thesis will discuss the men's experiences and perceptions in living with HIV.

## Conclusion

Risk is a feature of modern society (Beck 1992; Giddens 1990). Given the recent structural change in New Zealand it is argued that risk is another aspect of life to be self-managed. Such individualising of risk is evident in the health sector. My introduction has contextualised the following study of how we might theorise the impact of this individualisation of risk for ten HIV positive people. This beginning chapter focuses upon the detainment of four New Zealand men in 1999 for not disclosing they were HIV positive before unprotected sexual intercourse. I then went on to introduce the thesis and outline the following chapters. The thesis will proceed to focus on the living experiences of ten HIV positive men in Christchurch in the context of bio-medical advancements and how they view the increasing restrictions they experience as HIV positive people. The sociology of risk will frame an analytical discussion of the research and is introduced in the next chapter.

## Chapter 2

### Literature Review

Over the past fifteen years there has been an increasing body of literature in and around the issue of HIV and AIDS. However, there has been little research into the personal experiences of living with HIV (Adam 1992; Kalichman et al 1998) particularly in New Zealand. After discussing the available New Zealand literature this chapter will argue that Beck's (1992) 'risk society' is a useful framework to consider the experiences of HIV positive people. The sociology of risk will be complemented with more everyday and popular definitions of risk to support the thesis that risk is a social outcome of our modern society. The media, it will be argued here, has an impact in how these constructions develop. The sociology of risk provides a critical perspective from where the relationships the HIV positive men have with societal structures can be illuminated.

#### Current New Zealand Literature

Local social research into the lived experience of HIV and AIDS is beginning. There have been two major research projects in New Zealand which illuminate aspects of life for some HIV positive people. *Male Call/ Waea Mai Tane Ma* (Worth et al 1997a) was the first nationwide survey of men who have sex with men. Being quantitative research the study produced information about the sexual lives of 1852 New Zealand men. One report from this study (Worth et al forthcoming) considered the sexual experiences of the fifty five HIV positive men (4.2%) who took part. A regression analysis was carried out on the results. This revealed that the HIV positive

respondents were more likely to be on a lower income, older, unemployed and to use condoms for anal sex. Worth et al (forthcoming) note that stigma is an issue for HIV positive people and that HIV positive people may face financial hardship and relationship loss. The authors comment “it must also be remembered that until recently being HIV positive meant certain death after a period of approximately ten to twelve years” (Worth et al forthcoming, p22).

Worth et al (forthcoming) found that HIV positive men were significantly more likely than negative men to be attached to a gay community; that is, know other gay identified people and attend a range of social and recreational venues (Saxton et al 1998). They found 89.1% of the positive men were gay community attached compared to 70.1% of the negative men. There was little difference in the sexual practice found between positive and negative men (Worth et al forthcoming). The results here also note that HIV positive men have less anal sex than HIV negative men do.

In a qualitative study aimed at supplementing the *Male Call/Waea Mai Tane Ma* (Worth et al 1997a; 1997b) project McNab and Worth (1999) interviewed 31 HIV positive men using a semi-structured interview format. They focussed upon the process of sero-conversion from the perspective of the HIV positive men. This study is significant in that it is the first in New Zealand which looks at the lives of HIV positive men and aims to identify and analyse the socio-cultural contexts of the men's lives at the time of HIV infection. Their results show that those at high risk of HIV infection adopted safe sex practices; however, at the time of this adoption a number of men had already been infected (McNab and Worth 1999, p30). This research notes that there are a number of complex socio-cultural issues impacting on unsafe sexual practice. Risk taking, the researchers note, is an aspect of sexual relationships.

While published research about life with HIV is limited to the above reports there are a number of forums where the issues for HIV positive people can be raised. *Collective*

*Thinking*, a monthly magazine, is produced in Auckland by and for HIV positive people. In Christchurch, *The Ettie Rout Centre News* provides a local context and information to the people in Canterbury living with HIV and AIDS. Both of these allow HIV positive people an opportunity to engage with the issues they feel are central to them. These forums also provide connection for people living with the virus in rural and regional areas.

The requisite knowledge has to be built up via the exchange of information: in the context of HIV and AIDS education, 'talk' is often suggested as a route of risk reduction (Scott et al 1995, p162).

The 'talk' Scott (1995) suggests is achieved through the publication and dissemination of this literature. The new issues that confront HIV positive people can be raised in these forums. Stories written by HIV positive men have long appeared in community newspapers in the larger gay subcultures, and are available in this country (see *Sydney Star Observer* and *Express*). One recent article in *Capital Q*, a weekly Sydney gay and lesbian community newspaper, argued:

The attitudes of negative men towards positive men is a different area. You hear many stories from positive men about disclosing the fact that they have HIV to some new guy they are lusting over only to get a sympathetic few words and rushed goodbye. If this happens a number of times, and it can, its only natural that someone can end up feeling rejected and unwanted (Millan 1999, p9).

Millan (1999) discusses the sexually active HIV positive person in the Australian context. Jenkins (1997) reports on a relationship for a sero-discordant couple (partners who have a different HIV status to their own) in New Zealand. As with Haire (1998), raising the issue of being sexually active while living with HIV is central to Jenkins' (1997) article. Jenkins (1997) presents the HIV positive person as the one who discloses:

I never consciously thought of telling him. Suddenly the words were just out. And I couldn't take them back. But I felt comfortable that I could tell him.

The response to this disclosure is the partner saying that if they have safe sex it is "no big deal" (Jenkins 1997). The article is not centred on the difficulties of HIV disclosure or on the complexity in negotiating a sero-discordant sexual relationship. The opportunity here is to allow HIV positive people the sexual subjectivity held by HIV negative people. Jenkins (1997) and Haire (1998) allow the HIV positive man a sexualised role within their everyday life experience. My argument is that risks are part of our everyday life and sexual risks are aspects for HIV positive and HIV negative people.

#### International Literature

So far, very little has been done to identify the personal support networks available to people with HIV infection, the impact of illness on these networks, and their role in maintaining the quality of life of people with AIDS (Adam, 1992 p13).

As discussed earlier there is a beginning social research base in New Zealand on HIV positive issues. However, recent overseas literature can inform some of the current issues facing HIV positive people. There has been a growing body of Western international literature on life today with HIV. However, while this body of literature is important in capturing the living experiences of those affected by HIV and AIDS there is a number of competing research discourses in operation. There is not room here for a discussion in the various discourses available in HIV research, however suffice to say that sociology can assist in providing space for the HIV positive voice. It will be argued in this chapter that a sociology of risk extends an analysis to include the context of life with HIV and this involves support networks.

The concept of risk is found throughout the HIV literature. The uses of it as a concept and descriptor are varied and range from the social-psychological literature to the macro-sociological. Hart et al (1995, p58) argue that risk can be seen as 'social action' because risk is "endowed with meaning and negotiated within a social environment." For example access to condoms or threats of violence will impact on condom usage (Hart et al 1995). Social structure exists within this view of risk because inequalities of power impact on personal action. The components of a sociology of risk, identified in the literature, are power inequalities (Rhodes 1997), sexual scripts and communication (Deven et al 1997), community connection in terms of values and norms (Hart et al 1995; Douglas et al 1990), age (Hart et al 1995), habitualised practice (Rhodes 1997), love and a desire for intimacy (Hart et al 1995), erotic desire and pleasure (Kendall 1995); structural constraints (Hart et al 1995) and the relational aspects of sexual behaviour (Kalichman et al 1998).

In a comprehensive review of risk theory in relation to HIV Rhodes (1997) found norms are mediated through a social structure. He suggests unprotected sex is normalised through a heterosexual definition of intercourse. As norms are mediated through the social structure Rhodes (1997) argues that unprotected intercourse within a monogamous relationship is a norm. Therefore someone not connected to gay community may be outside of the safe-sex norms and not use condoms. Rhodes (1997) notes power issues are central to an understanding of risk. The power within a relationship, social enclave, sub-community and sexual activity needs to be borne out to illuminate how power may manifest in habitualised practice (Rhodes 1997, p220). Rhodes (1997) argues 'risk theory' in the time of HIV has positioned the individual as the unit of analysis. However, earlier sociological research has noted the importance of context and milieu in HIV research.

In a 1990 study Connell et al explore the sociological meanings of sexuality. The authors argue that the concept of milieu can be used to make sense of the interpersonal context of sexual lives. In their study Connell et al (1990) identify gay



community attachment (ie those men who have sex with men who attend or frequent gay identified locations, bars, sauna and/or recreational activities) as being supportive for the men while providing norms and mores around safer sex. The authors conclude that high-risk sexual activity (anal intercourse without a condom) is more likely for those men who are not gay community attached (Connell et al 1990).

Dowsett (1996a) also considers milieu an important aspect in HIV/ AIDS research. In his qualitative study Dowsett interviewed twenty men over a three-year period. All of the men had sex with men and some remained HIV negative throughout the study. However, some of the subjects sero-converted during the work. Dowsett (1996a) questions the usefulness in theorising about identity when the meanings the sexual person attaches to the process of sexual practice occur through interaction. He uses the example of anal intercourse and argues penetrative and penetrated carry a heterosexual meaning and are thus not useful in considering how two men engage in their sexual practice. Dowsett (1996a) allows the men in his study to articulate their understandings of sexuality and HIV. For Dowsett the language the men use is central to how the men make sense of their experience. One of the men in Dowsett's (1996a) study, Dennis, did not want to know of his HIV status. By disengaging with the medical system Dowsett argues Dennis is taking some control in his life.

In arguing that the self shifts and changes through a process of desire Dowsett (1996a) argues milieu is central to an understanding of the social processes and thus social construction of HIV and AIDS. For Dowsett (1996) it is the meanings constructed in milieu that are able to illuminate the experience of sex: "Recognising the interconnectedness of relationality and embodied sexual engagement is crucial to rethinking sexuality" (Dowsett 1996b, p27). Therefore, Dowsett argues for a rejection of identity politics and a consideration of what we do and the meanings we attach to the activity in order to study the way we live sexual lives. That is why research into the lived everyday experience of HIV positive people can assist in understanding the social challenges that may exist.

Two recent studies in Australia highlight the financial difficulties being experienced by HIV positive people. As treatments can provide increased life expectancy the person living with HIV faces accommodation, employment and financial pressures (Ezzy et al 1998). Social supports are another area identified in the sociological literature as central to the person living with HIV. Kimberley et al (1996) and Kalichman et al (1996) report that support structures are fundamental to the HIV positive person maintaining safer-sex practice. Both studies used survey data to compile a profile of HIV positive people attending support groups. Both studies also identified HIV positive people as seldom being examined in the research literature of support structures (Kimberley et al 1996; Kalichman et al 1996). While these studies were conducted in the United States they do have implications for my research as a sociology of risk includes an analysis of the changing relationships between structures in society and individuals.

This section has outlined a number of areas of social research available on life with HIV. As outlined, the international literature complements the available New Zealand research. Issues faced by HIV positive people in other neo-liberalist societies are of interest here but are tempered with the explanation that this literature review has only introduced this body of work. I acknowledge the vast body of literature available internationally, but as has been argued elsewhere there is a need for sociological understandings of life with HIV (Adam 1992; Kalichman 1998). Risk, as theorised by Beck (1992) and Giddens (1990), will be used here as a tool to assess the impact of structural change that is having an affect on ten HIV positive men in Christchurch.

## A Sociology of Risk

For Beck (1992) and Giddens (1990) a 'risk society' is one in which the production of risks occurs with the production of goods and services. Beck's (1992) thesis is that we live in a global society, one in which risks are produced that can go unnoticed and are uncontrolled by national boundaries. Risks therefore are diffused through society, potentially impacting on us all. Concerns over ecological uncertainty and the nuclear industry have produced a new set of potential risks for people today and future generations (Beck 1992). As a society we manage the personal risks around us. Beck argues that this management is achieved by relying on experts' knowledge and advice. For Beck (1992) the risk society is one where knowledge becomes an economic commodity. As such the media has a role to play in the production and consumption of risks. Beck argues that our society is one in which information, science and the media merge to culminate in a risk society. Risk, then, can be viewed as a cleavage in society which can cross national, class, ethnic, gender and age lines. The implications of this are that 'goods' and 'bads' are produced in our society. HIV, in Beck's terms, is constructed as a 'bad' or negative outcome. med.

For Beck (1992) society becomes reflexive, in that a reduction in constraints means individuals can actively reshape the world around them. For Beck, such reflexivity occurs at the individual level also. Reflexive biography occurs, Beck (1992) would argue, because a level of anxiety exists within the risk society; people become reflexive in order to exist within this context of anxiety. That is, people become aware of their relationship with society and how this impacts on their lives. This is a process of self-confrontation where the individual engages in the issue and this process becomes part of the person. Beck (1992) theorised that individuals become reintegrated through a process of reflexivity.

Individualization becomes the *most advanced* form of socialization dependent on the market, law, education and so on (Beck 1992, p131)

He argues that individualisation becomes institutionalised through the active positioning of self in society; that is, one's biography is transformed to accommodate society and in so doing transforms the world around them. This he argues is reflexive. For Beck this process is central to a risk society because the consequences of decisions made have an impact on our lives. These decisions may result in benefit or loss to the individual. Risk can be individualised because the consequence of a decision is seen as self defined; that is, the individual makes a choice and can be held responsible for it (Beck 1992, p136).

Individualism is not a recent phenomenon but, as Beck argues, there are components which are specific to our time. These include the removal of historically prescribed social roles, a loss of traditional security and a re-embedding in a new type of social involvement (Beck 1992, p127). For the individual then new freedoms emerge alongside a loss of stability in traditions. As social actors, Beck argues, we reintegrate into a new society in this context and an outcome of this process of individualisation is an increase in social control. Controls emerge because of increased freedoms. As the individual is encouraged to self-monitor behaviour social controls, for example laws and regulations, provide the benchmark for behaviours in society.

Giddens (1990), like Beck (1992), argues that the individual is a reflexive project in our modern society. Giddens agrees with Beck that risk is a feature of our time. Through the choices we have and make, Giddens argues, our identity is reflexively constructed. Life today, for Giddens (1990), is one in which identified risks are managed. This process involves both disembedding and re-embedding, meaning the individual can withdraw from an environment, locale or role, yet in withdrawing they rejoin (or re-embed) in another alternative context. Social change in what Giddens describes as a time of 'high modernity' (1990) has given rise to individualisation.

Therefore locating meaning in one's life is more complex. Life today means living with uncertainty.

Governments manage economic risk, industry manages environmental risks and we as individuals are encouraged to manage everyday risks. Experts are relied on to identify and reduce the risks we as a society may face. It is because of this, Giddens argues that, there is an acceptable level of risk in society. However, there is also a level of anxiety in society for Giddens and this operates in a climate of acceptable risk. *impl.*

It can be theorised, therefore, that living with uncertainty, for example living with HIV, could mean risk and uncertainty are interrelated. Luhmann (1993) defines risk as a "counter concept to security" (1993, p19). If finding meaning and security, as argued by Giddens (1990), is predicated on control and ontological security, the person with an HIV or AIDS diagnosis will have a different experience and understanding of security. Luhmann (1993) argues people calculate actions while factoring in risk. For the HIV positive person they have and, therefore, live with a virus that can be identified as 'risk'. However, as Beck (1992) and Castels (1991) argue, it is problematic to view risk in this way;

a risk does not arise from the presence of particular precise danger embodied in a concrete individual or group. It is the effect of a combination of abstract *factors* which render more or less probable the occurrence of undesirable modes of behaviour (Castel 1991, p287).

In arguing risk can be used as a 'new mode of surveillance' *however!* Castel (1991) questions the relations of power through which risk can be constructed. This, he argues, encourages self-monitoring as the traditional 'expert' is not needed to define the risk. In the case of HIV, Castel would argue, the transmission routes are defined and this information is made public. Therefore, Castel's argues the population self monitors (individually) the information they have. Within a neo-liberal paradigm, intervention, via a welfare system, is reduced (Scott et al 1995). This, Castel argues, means the construction of 'everyone is at risk' develops via public health education. \*

Castel's (1991) Foucauldian influenced theory extends Beck's and Giddens' work in that the analysis includes government action and the role this has on the production of the 'self'. In this thesis, however, the analysis will take the more late-modernist approach of Beck (1992) and Giddens (1990) because the theory of a 'risk-society', offered by Beck (1992), is sufficient to illuminate how life with HIV is problematised by a neo-liberal approach to health and wellness.

Risk, then, can be viewed as a consequence of the interplay of messages from the social actors in their networks as well as the media, opinion leaders, friends, partners and the individual (van Campenhoudt et al 1997, p70). Neo-liberalist approaches to welfare and health, however, define the messages of health and argue self-monitoring of exercising, diet and life-style are determinants of ill-health (Scott et al 1995). The media informs society of these options and can present an alternative 'bad' lifestyle to reinforce a public health approach. Thus, the media supports the 'everyone is at risk' thesis and offers visual images for our consumption. Beck (1992) argues the media individualises and standardises an issue in this way. If, as Giddens (1990) suggests, risk is an outcome of advanced industrialism and something that can be individualised, there will be a different experience for someone who is HIV positive than someone who is HIV negative. Giddens (1990) uses the term 'milieu' to contextualise the time and space of this lived experience. It is within milieu that the lived experience can be understood: "local milieu is the site of clusters of inter-weaving social relations" (Giddens 1990, p102). Trust and risk exist within milieu and are played out through social interaction. Having trust is to place faith and confidence in a person or situation. As Giddens (1990) argues trust means having 'confidence in the reliability of a person or system'.

Previous studies show that trust within sexual relationships is a variable in risk decision making; for example, trusting one's sexual partner to remain monogamous and having unprotected sex with them. This thesis will argue that a sociology of risk

can illuminate the complex interplay of relationships between sexual partners in a societal context.

### Conclusion

This chapter has outlined the sociology of risk as a framework through which the experiences of ten HIV positive men can be analysed. There is a beginning literature of HIV positive people's experiences in New Zealand. International literature raises issues for HIV positive people in similar societies. The media assists in the individualisation of risk and this was discussed here. Beck's (1992) analysis of a risk society is useful in understanding the impact of a located risk, namely HIV. My thesis is that the changing relationships between social structures and individuals result in risk becoming an issue of self-management. As has been argued social controls increase in a situation of increasing individualism. The impact this increase has on ten HIV positive people is the subject of this thesis. There are paradoxical outcomes for the men and their sexual partners.

I have also showed that there is a growing body of international literature on life with HIV. The sociological literature on risk (Beck 1992; Giddens 1990) can be complemented with other research about HIV. The research into the lived experience of being HIV positive in New Zealand is just beginning. However, a growing mass of international literature provides insight into this lived experience. This thesis will add to the New Zealand literature. A methodological discussion, of how this addition was achieved, is the subject of the next chapter.

## Chapter 3

### Methodology

In the actual practice of research, of course, one is faced with the need to constantly negotiate *between* the positions of insider and outsider, rather than being fixedly assigned one or the other subject position (Lal 1996, p193)

A participatory approach to this research was designed to address Lal's (1996) comment that negotiating between insider and outsider is a constant part of the research process. I had similarities and differences with the participants. These included sexual practice, sexual identification, HIV sero-status, gender and spatial and temporal experiences.

The process and practice of undertaking my research is the subject of this chapter. I have selected a range of issues that I feel encapsulate the process of researching this area. This chapter outlines why a qualitative approach was selected. I discuss my role as the researcher and place this within a context of having personal and professional involvement with HIV. The discussion moves on to the process of participant selection, the interview structure and issues that emerged during the research. The chapter will argue a qualitative approach with semi-structured interviews was necessary to gain insights into the men's lives and experiences. An essential component of this chapter is an evaluation of the methodology.

A qualitative methodology was selected to find out about the relationships of these ten men with the social institutions they are involved with. If, as Beck (1992) argues, we are within a 'risk-society', these men's experiences would illuminate the impact such a society is having on their everyday lives.



## Qualitative Research

Living with HIV means different things to each of the men. Massey et al (1998) comments that a qualitative approach to the study of resilience opens possibilities not available through a positivist approach. Assuming the researcher is not aware of all of the variables, a qualitative approach invites the participant to engage and become reflective about the presenting issues. A qualitative methodological approach allows my personal and professional experiences (described in Chapter One) to assist in the research process. These experiences form a basis for my involvement in HIV work today. In this chapter I will show how semi-structured interviews fit with this personal experience and thus assist the research process.

Social research can provide a focus on the context of the lived experience to be included in analysis. Dowsett (1997, p1), with reference to social research in health promotion, states: "...the first thing is to focus less on individual behaviour and more on the contexts of risk-taking and the social and cultural constructs that underpin behaviour change." Qualitative research favours an ethno-inductive format (Kellehear 1993) and as such, allows the researcher to study an issue in depth. I selected a qualitative approach because, as Patton (1987) comments, a full and in-depth study can be undertaken allowing the meanings and interpretations held by the participants to be borne out. Most importantly, this research attempts to locate the way these men see their lives with HIV today. It does not attempt to prescribe a lived experience for all people with HIV. For this reason a qualitative approach was selected to allow the subtleties, meanings, nuances and frameworks held by these HIV positive men to be illuminated.

Other researchers have noted the considerations involved in researching sensitive issues such as HIV (Bolton 1995) and representing gay men with HIV (Coyle 1996), as well as the problems inherent in researching sensitive topics (Lee et al 1990). Lee et al (1990) argue for a definition of sensitive topics in order to alert the researcher to

their responsibilities as researchers. Like me, Bolton (1996) and Turner (1997) have studied HIV positive men while being HIV negative. I found that, as Lal (1996) suggests, the process of research is one of constant negotiation between outsider and insider. One of the ways I achieved this balance was through having personal and professional experience in the HIV field. This allowed my personal knowledge of the 'street talk' to become a strength during the interviews.

Claiming the need for 'street talk', in the voice of the interviewee, Dowsett (1996a) argues for subcultural language forms to become voiced and then considered in the safer sex discourse. For example, inquiring into desire, without abstracting it or fixing it, is what Dowsett (1996a) sees as critical to further sexuality research. I included the 'street talk' Dowsett refers to in my question areas. Gaining insights from these men is predicated on a shared understanding of our interview discussion. This invites their participation in my research.

Semi-structured interviews were selected to enable the men to discuss salient issues relating to HIV. This was done for two reasons. Firstly, I wanted the participant to be able to develop their own areas of interest or concern. In this way the semi-structured interview questions provided a guide and prompt for the discussion. Secondly, I decided not to focus directly on sexual issues. This would allow sexual practice to be discussed if it was an issue or a development during the interview. With the recent media coverage of the arrests of HIV positive people most of the participants were eager to discuss this situation. As semi-structured interviews enable a flow of dialogue between researcher and participant the collected data is a result of an interactive process.

Previous studies were reviewed for methodological issues. A qualitative study of the social issues facing HIV positive gay men in Toronto used focus groups and was conducted by the AIDS Committee of Toronto (ACT). Maxwell (1998) supported a qualitative approach to his research. His study is significant to my study in two ways,

Firstly, Maxwell, like me, is involved with a local AIDS organisation and, secondly, the findings from his study indicate areas of focus for the Christchurch study. Semi-structured interviews and a grounded theoretical approach (Glaser et al 1967; Layder 1993) is supported in the literature for this type of research (Lupton et al 1995). There are other methodologies employed in similar studies: Focus Groups (Maxwell 1998), Survey (Worth et al 1997a) and Life History (Dowsett 1996a; Turner 1997; McNab & Worth 1999). Working in adjunct to each other allows additional understanding and insight to the issue under study. Thus, qualitative and quantitative methods work together to provide insight and depth to an issue (Reinharz 1992).

### The Research Process

A review of the available literature on life today with HIV was undertaken. From this literature search, and my experiences, I selected four topic areas which I felt would cover the range of personal experiences for the participants. In not focussing directly on one topic a range of issues were borne out during the interviews. Four areas were chosen to facilitate discussion. These areas invited a wide discussion of life today with HIV:

- Aspects of the everyday
- Support structures
- What has changed post HIV diagnosis
- Connection to gay community

I wanted to allow the opportunity for the discussion to intersect the four areas. For instance, sexual negotiation may feature in aspects of the everyday and post-diagnosis changes. This would allow a participant to return to an area already discussed and

add to validity issues that Fielding (1993) raises in qualitative research. This approach can address any discrepancies between statements, in what Fielding (1993) calls tightening the fit between what people say and what people may do.

Selection of these men was based on a number of criteria. Firstly, they had to have an HIV positive diagnosis. The person had to be diagnosed over twelve months ago to allow some time to adjust as HIV positive and, hopefully, comfort in discussing the associated issues. Secondly, the men must live in Christchurch as this is where the main gay community structures are. Thirdly, the men are or have been men who have sex with other men. The men did not have to identify as gay. Selection was done through the Ettie Rout Centre, the Christchurch office of the New Zealand AIDS Foundation. In line with the ethical approval granted by the Canterbury Ethics Committee, and the Canterbury University Human Ethics Committee, the study was discussed individually with clients of the Centre by the researcher. An information sheet was offered to them outlining the study. Two weeks later the participants indicated their interest or non-interest, in being involved with the study. A number of men had questions about the study and these were addressed. One man, who does not speak English, was approached with the assistance of a translator. Following this a time and place for an interview was arranged with those who voluntarily agreed to be involved.

A short demographic form, which can be found in Appendix Five, was completed after the interview and served two purposes. Firstly, it provided information on sexual identity, age, education, ethnicity, income and employment. Secondly, it allowed for a discussion on clarifying issues that may have arrived during the interview. In asking the men to define sexual identification, sexual orientation and sexual practice I was able to consider their responses in light of the transcript data.

### The Research Practice

In May of 1999 the ten HIV positive men were interviewed for this research. The participants ranged in age from twenty to sixty-six. The average age was thirty-seven years old. Nine men rented their homes while one owned his with another person. Two men are currently in full time paid work while eight are on Work and Income New Zealand (WINZ) benefits. None of the men are doing unpaid work. One of the men has completed a tertiary qualification. While all ten men identified as New Zealand European/Pakeha three selected an additional ethnic identity. These three men identified as being descended from New Zealand Maori. Two of these men could name their iwi (tribe). Another interesting aspect of the participants' current lives is that only one man is currently in a relationship of six months or more with his partner. Another of the participants does not speak English. A translator was used in the interview, who translated verbatim in order for the meanings as held by the participant to come through. Of the ten men in this study eight identified as gay or homosexual. The ninth identified as bi-sexual and the tenth heterosexual. All ten men are or have been sexually active with other men.

Eight interviews took place in the participant's home and two in the office of the Ettie Rout Centre. The interviews ranged between one to two hours each and most took two hours. The topic areas were used to frame the interview with thirty minutes set aside for each. I advised the men that if a topic was uncomfortable for them we could move on at any time. Some issues were discussed across sections. This allowed me to refer back to earlier sections and prompt for further details or seek clarification. The discussions around sexual behaviour occurred later in the interviews, when comfort and rapport had been affirmed.

As I expected, talking with the men about everyday life issues with HIV was the most straightforward section. The interview with the man who speaks another language

was the most difficult as the general discussions that had occurred in the other interviews were not a feature here. I scheduled this interview last for two reasons. Firstly, arranging a translator the participant was comfortable with, as we would be discussing very sensitive areas, took time, and secondly, this interview would be different from the others because of the translator and translation. I was aware that subtleties may be lost during translation; for example, 'suck' may be translated as 'oral'. When thinking about the 'street-talk' Dowsett (1996a) suggests for this type of research I met with the translator and discussed this. This achieved a relaxed atmosphere during the interview. It also allowed the participant's understandings and experiences to be captured here.

The interviews were audiotaped and tapes transcribed verbatim. The men were contacted when the transcripts were ready and invited to make additions or alterations. A number of men made only minor adjustments. All identifying information was then changed. The transcripts were coded into themes. The sets of relationships these men have in society were identified and coded. The reassembling of themes into categories was checked against the initial transcript. This is in line with what Kellehear (1993, p39) notes:

Thematic analysis ... takes the data itself as the orienting stimulus for analysis to overcome etic (outsiders) problems of interpretation by staying close to the emic (insider's) view of the world.

This study considers the relationship between the person and society, and while it remains grounded in the experiences and interpretations of the HIV positive men, provides insight into the power dynamics that impact on them. In considering the structural phenomena in research Layder (1993, p55) argues power issues are illuminated because "institutional or structural features of society are intimately interwoven with behaviour and activity." An insight into these men's lives would provide their perspectives and the ways they see social institutions assisting or inhibiting their lives.

In an exploratory process semi-structured interviews were designed to allow participants an open ended response option. This also allowed freedom for the person to respond in the way they chose, thus allowing their interpretations and meanings to surface (Layder 1993). Locating the researcher into the research is achieved in a grounded technique because the researcher is “an active sampler of theoretically relevant data” (Layder 1993, p44). The literature review and my experience informed the relevancy. Focussing on risk and the relationships these men have with social structures provided a direction for the research. Semi-structured interviews allowed the voicing of issues salient for the men.

I have outlined the research process and practice in the above sections. This section will evaluate the methodological approach I took. Other HIV negative researchers have studied HIV positive men (Bolton 1996; Turner 1997). It was my professional role that assisted in access, engagement and rapport. During this research my connection as the Social Worker at the Ettie Rout Centre provided me with a professional identity, as I was known in this role to most of the respondents. While the issue of my HIV status did not present, my relationship with the participants was such that they expressed confidence in my work and position as a staff member with the New Zealand AIDS Foundation.

Validity was considered during this process. Turner (1997) argues there is a discrepancy between what people say they do and what they actually do. He suggests validity of interviews into sensitive topics can be increased through matching interviewer with interviewee (Turner 1997). The research was designed to need only one interview and the fieldwork was completed in ten days.

A longitudinal study would illuminate further aspects of these men’s lives and this study may provide insight into how this could be done. Other methods such as participant observation may also provide aspects of interaction in the gay community,

again assisting this study to develop the categories found. However, discussion of sexual activity is sensitive and problematic in social research (Coxon 1993). The use of semi-structured interviews allowed for flexibility and openness in the discussion. While this occurred in nine interviews the tenth was a different experience. This method was limited in use when there was a language barrier. Through a translator the participant responded to my questions, however there was no development into a general discussion. Insights into this man's life were gained from this process, however this interview lacked the richness of the others. A more directed interview schedule could have been used in this case.

The establishment of a rapport and outlining the study enabled the participants to be open with me. Overall, as a researcher I could reintroduce various topics during the interview. This study does not set out to prove or disprove the findings of previous studies but seeks to present the meanings these men place on their sexual and social experiences at this time. The participants were included in the research process, through the direction of questioning as well as the reviewing and editing of transcripts. For instance, one man asked if HIV could be transmitted through water. This may not have been a question he would ask in a different context. During the research process I was able to provide information on services and technical matters, like drug names, again highlighting a participatory aspect to my field research. If this work can be used to provide understanding in social policy, social work practice and give clarity for people living with or around issues of HIV, then the participation of the men in this study can extend beyond the realm of this particular research. Being part of a research project invites the participant to consider their role and perspective.

Reflexive research recognises that the research object is not static, a photograph that is once taken and forever captured (Dowsett 1996a, p41).

As Dowsett (1996a, p41) comments, the research process has an impact for the participant beyond the fieldwork. A number of men asked for follow up information to be sent out and nine requested some form of outcome from this study. The recent arrests certainly had an impact on the men's responses when talking about their sexual



behaviour. This fieldwork occurred between the arrests of two HIV positive men for non-disclosure and the resulting recommendations by the New Zealand AIDS Foundation for HIV positive people in June of 1999. If this research is repeated the results may differ due to the increased awareness of disclosure issues and the new definition of non-safe sexual activity as a criminal offence.

The study consisted of ten men and while this illuminates their experiences this study does not intend a generalised experiences for all people with HIV. A more structured format may have provided more detail when a participant and researcher speak different languages. Some of the experiences were retrospectively told. Using journals and diaries may provide additional areas of discussion for the participants and researcher. This study was designed to reflect the experiences as seen by the HIV positive person. Including significant others in a study like this may cloud the discussion from the participant. However, it may also provide interesting insights into the management issues confronting HIV positive people today.

### Conclusion

Semi-structured interviews allowed a developmental approach to the research. This meant a topic of interest, concern or something the participant or I raise could be discussed. Research into life with HIV is just beginning in New Zealand. This chapter has outlined the methodological and practical considerations in undertaking my research. I situated my experience as an HIV negative gay man living in New Zealand today in an earlier chapter. Semi-structured interviews were used to allow my personal experience to probe participants further into some areas. This chapter has outlined the process and practice of the research. Through an evaluation of my methodological approach I have shown that semi-structured interviews are an effective tool in researching sensitive areas. I have also highlighted the limitations of

this method when there is a language difference. The findings from this research are presented in the following two chapters.

## Chapter Four

### Findings -

### The Social Construction of Risk

The changing relationships between social institutions and individuals are a feature of the risk society (Beck 1992). The previous chapter argued for a methodology that would illuminate this relationship for the ten HIV positive men. This chapter is the first to discuss the study's findings. Firstly, I will outline the men's perceptions of their relationships with the social institutions they are involved with. This outline includes a section on the impact on these men of the media coverage of the recent arrests. This is the context of risk for the men. The chapter will then discuss reflexive biography (Giddens 1991) and argue that such an understanding of 'self' is an ongoing aspect of these men's lives. The third section of this chapter is called Personal Responses and details the taking of some control by three men, through ceasing medication. This discussion includes comment on how this understanding of self impacts on the men's sexual lives.

The changing relationships these men have with society are a central aspect of this chapter. The argument here is that these men see themselves as individuals with HIV and not as a collective. Beck (1992) would argue that this may result in anxiety for the HIV positive men. He also argues HIV is localised as *the risk* and, as such, security for society is managed through the positioning of the HIV positive person as the infector, or site of infection (Beck 1992). The men reflexively engage with HIV and this engagement highlights how the construction of risk in society has an effect upon these men. Risk then, can be localised, and this occurs within the context of our society.

## Society

### Institutions in Society

As expected, these ten men are involved with a number of social institutions, including the New Zealand AIDS Foundation, hospital clinics and general practitioners. However, a number of institutions operate outside of the men's direct day to day lives, such as the police, legal frameworks and social policy, yet from time to time these institutions affect the men's lives. Eight of the men are currently financially supported by Work and Income New Zealand (WINZ). Two of the men in this study have had what they describe as negative reactions from WINZ staff. That is, they perceive the staff to be treating them differently from others because they have HIV, for example,

they look down their noses at you because you're positive. I thought 'fuck you, who are you to bloody look down at me like that, it's all right for you pushing buttons on the computer. You are the one who is ruling my life' (Shane).

Shane's perceptions of the caseworker leave him feeling 'controlled' by WINZ. He adds that he believes the staff lack training in this area (HIV).

They should be trained better to be able to deal [with HIV]. They don't even understand what HIV is, they don't, and they should have staff working in there that are trained on various issues, just not necessarily HIV (Shane)

Men on sickness or invalid benefits need their doctor to complete a section of the application form and, thus, outline their condition. While this information is included on the WINZ file, the other six men are not concerned about who may have access to their file. Two men state the WINZ staff are 'good' and in one case, 'very helpful'. One man adds that the staff are professional and he believes they would be

confidential about his HIV status. The other six men currently on a WINZ benefit see this agency as a part of their life.

While all of the men have some connection to the hospital, local New Zealand AIDS Foundation office and general practitioners they experience these services differently. Most of the men describe the Infectious Disease specialist as “busy.” Appointments with the specialist vary from three to twelve monthly, and they last about twenty minutes. The experience of doctors also varies in terms of levels of knowledge and perceptions of care. Some have exercised choice in the selection of a doctor. For some men having a gay doctor is essential. Others changed doctors on diagnosis. Nine of the men in this study were diagnosed in a doctor’s office or hospital setting. One was diagnosed at the Christchurch office of the New Zealand AIDS Foundation Office, the Ettie Rout Centre, after the suggestion by his doctor that his current medical condition may be related to HIV. The men talk of shock and disbelief on diagnosis. Ricky is typical of this reaction:

I was at the hospital and under [a] specialist there and um, it was him that told me and I remember being absolutely devastated because it wasn’t even my own doctor. It was a complete stranger.

In his comments Ricky captures the moment of diagnosis for him and his associated feelings. For Ricky, the diagnosing doctor was a stranger. The majority of New Zealanders diagnosed as HIV positive are advised of their condition in a doctor’s office (Dickson 1999). This relationship with a doctor is seen as central to the men in this study. However, communication, while open, appears to be directed by the medical staff. Alister captures this idea nicely.

They don’t ask about depression or nothing like that just mainly how are you feeling physically and stuff like that.

Alister highlights the bio-medical focus he perceives in his health care. Alister’s depression is not discussed in this context. A number of the men explain that they feel

left out of the relationship with their health professionals. For example, one man received a letter at home indicating a change in his blood level readings.

I got a letter from my GP saying he had reviewed my notes and noticed that two months ago my viral load thing was such and such a level and I just went into tail spin because I knew from my readings that 10 - 15 was sort of like, and then over 15, from my understanding is, doesn't matter what your CD4 count is if your viral load's over 15,000 you can go on to medication and my viral load came out at 154,000 and it just sent me into complete and utter tail spin, I mean I was just going up the wall by then but the information I got from my GP was well you know, this could be turning the page in the book, you've got to look at, you may have to go on to medication and that was a huge issue for me, absolutely huge and um, I just couldn't figure it out, I just felt absolutely sick inside (Ricky).

This example of Ricky's experience captures the perspectives of patient and doctor. Both experience this information in different ways: the doctor sends the information out in a format standard for them. The patient receives this at home after work and is left until the next day to speak to the doctor to clarify the issue. For Ricky this was a difficult night. While he had a level of knowledge he felt comfortable with the letter left him questioning his understanding, and thus his sense of control. Ricky has a support base of friends but did not discuss this letter with any of his friends that night.

The men accept the medical treatment they receive. There are several reasons why this may be so. For example the cost of health care varies for the men with some paying nothing for GP care to a part charge for others. This has implications for a patient who may not want to complain.

I do feel very grateful for that fact that I don't have to pay for a doctor or specialist, so I guess because I feel grateful that I don't have to pay for anything I take it as it is (John).

John's experience of 'taking it like it is' suggests a passive position in his relationship with his doctor. While medical practice operates in an inclusive model, Kutner et al (1999), find difficulties in communication between doctor and terminally ill patient

through their discursive analysis of doctor - patient consultations. Kutner et al (1999) recommend a client centred approach in a field focused on biological determinism.

Given their passivity in terms of specialist and health care interaction the men's options to extend their knowledge in this context appear limited. This finding adds to a recent survey conducted by *Collective Thinking*, a monthly magazine produced by a national collective of HIV positive people, their carers and supporters (Reid 1999). This survey indicates that the readers were five times more likely to be HIV negative than positive and that the most read articles were drug treatment issues. The Christchurch study finds that while the men enjoy receiving the literature they perceive these articles at times to be complicated and beyond their technical level. Therefore, any confusion around drug treatments or medical care may be left unaddressed and this may increase the risk of drug compliance problems.

Another institution having an affect on the men is the police. The arrests of HIV positive men are raised as concerns for the men I interviewed. All of them were aware of the arrests either through media coverage, being told by others or a direct involvement with one of the cases. Some of the men link the current police action to a 'witch-hunt' process. John is typical in his view of the police.

Are we all going to be questioned and held up in front of the Police Sergeant and asked about our sexual history. I thought this sounds like a horrible witch-hunt. I mean the police are pretty bigoted.

The perception that the police are against HIV positive people is expressed by a number of the men. One study participant was interviewed by Health Officials in relation to the arrest of two HIV positive Christchurch men. He was implicated as a possible sexual partner by one of the men. He explains that health officials visited him and requested he co-operate with the police in their investigation. Murry told me the

health officials not only confirmed the detained man's HIV status but also encouraged Murry to become a police witness.

[They came] to tell me that my name had been put forward as been having sex with [the detained man], and they wanted to make sure and see if I would talk to the police...just to say that I had [had sex with him], and he is [HIV positive], and I'm a police witness sort of thing. They just wanted to know if he [the health official] could have an interview with me and tell him what happened, when, where and why. I said no. I said I would have the interview, yes, but I would sign nothing, nothing will be signed (Murry)

There was a risk for Murry in becoming involved with this issue as he indicates the officials were seeking clarification about his knowledge of his partner prior to having sex with him. Murry refused to sign a statement and withdrew any involvement. Murry reduced the risk of his HIV status becoming an issue through his withdrawal.

There has been an observed increase in police surveillance after the arrests. As Peter comments "The police are looking around Hagley Park all the time now." He told me that he regards 'cruising' in the park as "too dangerous." That is, Peter identifies the park as a site of risk. Peter has been questioned by the police, in terms of being in a park, and he has this response ready for further police questioning: "if the police try to arrest me I'd say 'hey [I speak another language] and they'd let me go, wouldn't they.'" One positive example of police action was given however. One man explained that the police were known to collect young people who may be loitering in parks or public toilets, seeking sex, and escort them to sex-on-site premises. There are two of these premises in Christchurch providing a staffed secure venue for sexual activity between men. Aside from this one example, the men overall perceive the police as agents of surveillance and control.



## Media

HIV is in the media from time to time in this country. The charges in Christchurch in April 1999 of criminal nuisance for two HIV positive men gained extensive media coverage (see appendix 6). As indicated with the following quotes the media has a powerful ability to construct HIV as an issue for society. The men describe how this coverage left them feeling.

It was like fuck, what the hell is this and I couldn't believe that he [an arrested HIV positive man] had been named... it was like a flashback, almost like a flashback to like ten years ago when I was twenty, to some of the stuff you used to see in the mid 80s (Bruce).

It fucked me off Tony because that puts, that reflects on to me, you know a lot of people going 'Shane could be the same, he could be doing the same thing' (Shane)

It upset me for the first night or two. I couldn't really sleep because I suddenly thought 'is this going to be a witch-hunt? Are they going to come after me now, are they going to come looking for me because I've got HIV?' (John).

That devastated me, I mean really, I felt sick, for the fact I thought, what a bloody witch-hunt. And I thought it was absolutely disgusting because also it was attacking someone and I turned round and thought 'my god that could so easily be me' because I go 'oh I don't disclose' and I've got no reason to and no one tells me I have to (Ricky).

Bruce is reflective, Shane concerned about others' reactions, John is worried about further police activity, while Ricky captures an aspect of tension in terms of not being 'told' to disclose and so not disclosing. The media has an impact on how these men perceive society's view of them. They are aware that others will be reading the same newspapers. However, a discourse of silence operates to isolate the men from any communal response. Shane doesn't challenge the possibility of this being implied about him. John's fear of a 'with-hunt' is a private experience, one that keeps him

awake at night. Ricky's physical reaction represents an internalised response to a situation he sees as possibly impacting on him.

The media works to present the risk to the public. In this way the risk is identified as HIV positive people having unprotected intercourse. The arrests and detaining of the men works to situate the risk within the body of the arrested man. The risk of infection is removed through containment of the 'body'. Beck (1992) argues the media can isolate and standardise an issue through mass presentation. In this case the four men quoted above consume the construction of risk presented in the media and this in turn becomes part of what Giddens (1991) calls reflexive modernization. The individual engages with the issue presented, considers action or possible outcomes and this engagement and consideration in turn become part of this person's approach to the situation (Giddens 1991). For these men there is a risk that they could be questioned by police, detained or even implicated as having sex without disclosing. As Ricky states, he has no reason to disclose as no one has mandated this. There is a new risk here in that, because they are HIV positive, they could be identified as sexually active. A decision to manage this situation is made. Risk is not the outcome of this media coverage but exists in and through the media discourse. Giddens (1991) refers to this as reflexive biography.

### Reflexive Project of the Self

An aspect of the risk society for both Beck (1992) and Giddens (1991) is reflexive modernization. Individuals are also reflexive and Giddens (1991) argues the self is "reflexively understood by the individual in terms of his or her biography" (Giddens 1991, p244). The experiences the men have with WINZ, the police, health officials and other gay men impact on how they continue to engage with these structures and manage ongoing interaction. The men understand their place in society in terms of

these relationships. As discussed above, the men are involved in a number of social arenas. This section will discuss the narratives the men use in their lives with HIV. I will argue that these narratives are produced in the men's lives through interaction in a society they see as negative toward HIV positive people.

The men do not see themselves as reflexive. For example, the men see HIV as an aspect of their lives but not an identifying feature. None of the men referred to themselves as 'a positive man' or 'an HIV positive man.' Three of the men indicated iwi (tribal) connections, yet none of them hold current links into hapu (sub-tribe) or whanau (family) structures. The men with Maori iwi (tribal) connections indicate a need to focus on their Pakeha (Western) lives. This section supports the argument of my thesis that these men individually manage life with HIV and the risks associated with it. These men are aware of how society views HIV and the sexually active HIV positive person. Thus, they reflexively manage their HIV status accordingly.

### Reflexive Biography

The disembedding and re-embedding (Giddens 1991) of the individual within society highlights how people can manage risk. For example, the monitoring of one's health shows the interaction between individual and health workers. Within this interaction the individual may reject advice or make changes in lifestyle to accommodate the suggestions of medical staff. This process, of confronting the issue, is reflexive because this confrontation becomes central to the decision made. The confrontation of issues and asking of questions leads to the reordering of narratives and to what Giddens (1991) calls a reflexive biography.

Self-identity, Giddens (1991) would argue, is a product of this reflexively organised project. Beck (1992), like Giddens, argues that the self is a product of reintegration

with a number of social institutions; this ongoing aspect to life occurs within a context of secondary institutions.

HIV, viewed within New Zealand's neo-liberal society, is subject to the secondary institutions which Beck (1992) argues impact on how HIV is viewed and understood by both positive and negative people.

There are three types of reflexive biography used by these men. Firstly, acceptance was identified in two of the men. These men hold philosophical views of where they currently are; one of these men described living with HIV as "another test" in life. Knowledge about themselves with HIV is central to these men.

Having that knowledge empowers me whichever direction it goes because it gives me the ability to make a decision on what I know (Ricky).

Yeah, I want to know what's going on. I feel it is, it's important to know what's going on ... [I] read all the conference news and tests and drugs and what's coming up and what's available (Warren).

Paradoxically, this comfort in accepting an HIV status means the management of being exposed as HIV positive can be countered early on. Ricky captures how this is managed: "I'm certainly there as a gay man [in a sauna] but a positive gay man with a cock but that's my knowledge." This man makes a decision to not share his HIV status and guards it as private information.

Insurance is another example of a decision not to disclose. One man questioned future insurances, for instance mortgage insurance. Again, managing the risk of being rejected is done through not divulging the information. This operates because this man is reflexive about HIV issues. His biography, for insurance purposes, becomes one of HIV negative.

Huge, I mean I've got no life insurance. God I didn't want anyone in hell to know I was having an HIV test, because it is the insurance issues. I mean you know, I'm looking at getting a mortgage for a house (Ricky).

Secondly, a group of men see HIV as external to them. This group removes the issue of HIV from their lives as a risk management strategy. These men hold alternative health narratives, including 'heart conditions', 'cancer', 'being ill' and, paradoxically, 'being well'.

All they know is I've got cancer, but I'm not lying to them. I'm not, coz it is a form of cancer. He [a sexual partner] knows I'm not well. No, as far as he knows too it's cancer. Coz I'm not lying to him either (Andrew).

Andrew uses the cancer narrative reflexively here in that he incorporates the narrative into his sense of self. A cancer narrative informs his partner that he is 'unwell' while leaving HIV outside of any sexual negotiation. The men who use the cancer narrative position themselves as central to the story. They develop their identity as living with a health issue they cannot control. Overall, these men externalise HIV as an issue they can then remove from their lives.

I'm not a person to talk about it all the time, no forget it, chuck it out the door, because you can't think like that all the time. You can't eh (Shane)

This man removes HIV from his life through the externalising process. In not acknowledging HIV the issue is removed from focus. This coping skill is employed by a number of the men. The reactions from other people impact on the way the men perceive themselves as HIV positive. One man describes being 'infected' through a rape, while one struggles with the possibility that he has infected someone else. Others see the person who had infected them as 'the infector'.

Oh I wanted to know, so whoever it is can be done something with. But the one they've got now they think was, I don't think it was. It's only since that last couple of weeks ago [following the media reporting of an HIV positive man being arrested] (Murry).

This man begins to consider himself as the 'infected' by another. In light of the media coverage he incorporates this aspect into his biography. The risk of being identified as an 'infector' is countered with a narrative of being the 'infected'.

Thirdly, the last group of men can be described as preparing for life with HIV. These men consider issues of the past and ask how HIV may affect their lives. One common experience is not being ill and, thus, having a feeling of optimism in terms of HIV progression. This optimism is couched for some of the men in terms of a reality of HIV being ever present. The coping ability varies for the men as they adjust to the experience of living with HIV. Overall, for this group, the experience is one of HIV 'being there', almost outside of the everyday lived experience. Some men remain philosophical in terms of seeing HIV as 'something there', although unwelcome. The connection between staying well and optimism was expressed clearly by Warren,

Makes you feel more sort of optimistic that you're going to stay well, um, I suppose ... basically makes you feel optimistic you are going to stay well with the...as time goes on and the drugs are getting better if anything comes to the point where you need to go on them yeah.

This man adapts to the risk of becoming unwell through sustained optimism, a term coined by Giddens (1991). Warren manages the risks through what he describes as taking care of himself. Giddens (1991) argues this sustained optimism is a coping mechanism, something to balance the anxiety that is a feature of a risk-society. While the men see the virus as within their bodies and cope with this in the ways outlined, they also acknowledge the effects upon their lives that treatment advancements have had or may mean.

Oh they're fucking major, they're really, really, really major and it's quite scary, um, it's just like you've gotta, it's starting all over again, you are starting all over again and I mean you've virtually starting from scratch, you've got to, everything gets re-evaluated, everything (Bruce).

The social aspects of life with HIV today occur within the context of advancing drug treatments. As Bruce describes, re-evaluating an extended life is an enormous issue and impacts on everything. Some keep a day to day focus, some reconsider plans, while others wait for illness.

There are two distinct ways the men cope with their HIV positive condition. Firstly, they confront HIV as an everyday reality and plan around it. The older a diagnosis the more comfortable the men became with an HIV condition. These men have found ways to reduce stress by incorporating HIV into their daily plans. This was not always as straight forward as hoped.

One thing I will say is when you get something you think 'oh my God', like I get cold sores and then every time you get a cold sore you think 'oh my God' because that was one of the first things, oh you know, Herpes Simplex is one of those things and you may have to go on tablets, so every time you think you get one you think 'oh my God is this the start?' (Ricky).

The second option is to reduce planning to a daily occurrence and thereby isolate HIV issues to the minimum. This 'living for each day' occurs for the men who had been more unwell than the others. The adjustment to being HIV positive varies for the ten men, as they were diagnosed at various times between 1986 and 1997. Both confronting HIV as a part of life and minimising the virus require a narrative to make sense of daily life.

These narratives provide meaning and understanding about how they became infected and perhaps how HIV can be explained to others. However, the men remain grounded in a reality of today. Some of the men had made plans around living a shorter life. Now those plans been revisited and adjusted. This planning around a longer life means consideration of income, returning to work, increasing medical costs and a re-entry into a society often negative and problematic for people with HIV.

One man re-prioritised his weekends and comments about how hard he worked prior to his HIV diagnosis. Time with his partner has developed new meaning because he is unsure about how much time he may have. Another man in his early twenties has re-evaluated his desire to have as much sex as possible.

All I wanted to do was just go around and screw and stuff like that, be normal you know, just do that. All I pretty much wanted to do was just like get a car and just be cool, you know, but know stuff like that's like pointless. It's like why, I don't need that to be happy (Alister).

Alister is reflexive in his understanding of himself today. Understanding HIV through increasing knowledge is another feature of the men's lives. The men demonstrate that knowledge was not always consistent with action. For instance, Murry asked if HIV could be transmitted through the water in Hanmer Springs, a thermal reserve close to Christchurch. When asked if this would restrict his attending the springs he replied, "It would restrict me but I would still go." In another example Ray uses the HIV test as a measure of his status. As he explains: "I was sort of aware, sometimes I'd say I'd rather not do that but that was about it." For Ray, feeling powerless while being sexually active means, paradoxically, that he is unable to translate his knowledge into a framework to be used proactively for sexual practice. The HIV test becomes the benchmark for his sero-status and not his own knowledge base.

Through an engagement with social institutions and other people, the men reflexively incorporate others' view of HIV into their lives. For some a narrative of acceptance means alternative stories are easily accommodated. This process is reflexive in that the men confront the attitudes and understandings of others and this confrontation is incorporated into their stories of self. The men manage the risks of being exposed as an HIV positive sexually active man through what Giddens would call a reflexive project of the self.

As the men face HIV directly as an issue in their lives they operate within a continuum of reality spaces. This is what Annandale (1998) refers to as the reflexivity of facing



death. The two options Annandale (ibid) suggests may occur for terminally ill people are a search for meaning and living life to the full (or maximising what is presently available). Living within one of these frameworks provides what Annandale (1998) describes as a tension.

The fragmentation of public discourse by private experience is manipulated by expert knowledges of various kinds, and the individual is faced with a paradox of control and dependence (Annandale 1998, p254).

The control and dependence paradox is highlighted in the next section about a number of men ceasing drug treatments that had shown biomedical improvement to their health. This decision occurs in a context of managing the risks associated with drug treatments, disclosure and the possibility that the virus will retake control in the body.

### Personal Responses

A reflexive biography (Giddens 1991) is one where the context is engaged with, and confronted and is, thus, self confrontational. As discussed, these HIV positive men use narratives around illness and wellness to include others. This approach also works in a climate of anxiety, one that Giddens (1991) argues coexists in a risk society. Anxiety is a feature for these men at this time because of an increasing interest in the sexual lives of HIV positive people. Taking control of one's life (in Giddens' terms disembedding and re-embedding), then, is one way to manage the anxiety. This control has implications for the HIV positive men and their sexual partners. A discussion of the men's sexual lives will show that the changing relationships these men have with social institutions produces a new range of risks for the men and their sexual partners.

### Sexual Risk

While only one person in the study is currently in a relationship of six months or more, all ten experience levels of stigma in sexual practice while being HIV positive. One man uses the words 'infected' and 'infectious' with reference to him being sexually active; other men use 'outcast' and 'leper.' As Warren explains,

people with HIV they get, [they] feel as though they shouldn't be having sex because they're positive and people, you feel that a lot and that um, people should be told before you have sex with them if you are HIV positive.

The tension involved in managing possible stigma in sexual activity is articulated by Warren. He expresses a tension in having the information and retaining it, thus maintaining control. All men have had a period of adjustment in resuming a sexual life post diagnosis.

Um.....about eighteen months, eighteen months sort of between being diagnosed and um...then started having sex again, it was about eighteen months ... just took it slowly, till you got used to it, you know (Warren).

As with responses to media this adjustment is largely a private experience. The men all had a period of celibacy post diagnosis. The men became aware of how other sexual partners view HIV and how this view could be internalised and managed through strategies such as an avoidance of anal sex. If the HIV positive man is 'cautious' yet not willing to disclose then the other partner may take a leading role in sex. Research indicates HIV negative men assume their sexual partner is negative unless told otherwise (Fisher et al 1998). This will produce a tension in sexual practice for the positive man.

Six of the men stated that anal sex, active or passive, is no longer a central aspect of their sexual lives. Closely connected to this change in sexual behaviour is the issue of

condoms. Condoms present different issues for the Christchurch men. They represent 'protection, safety, a barrier, a reminder, a necessity and cleanliness'. For one-man condoms make him "feel dirty" while another commented that "a lot of people don't like them." None of these men express positive views of condoms in terms of enjoying sexual activity. Comments like "you should use them" and "they are necessary" suggest a mandated experience. Hence, the men have developed different sexual activities, with one man moving into more esoteric sexual practices including light bondage and role play. There has been a shift in focus from anal intercourse to a different base of activity for the men.

The men also reflect on their sexual practice before being diagnosed and use words like "normal sex" and "hot" to describe such practice. This suggests condom use has been adopted post diagnosis. John captures this perception.

To me they are a *necessity*, that I have to use that. I don't really want to. But then when I am drunk I still have my wits about me to use them. I'm not one of those people that suddenly once they've had a few drinks all hell is blown to the wind. But I know people who are, once they've had a few drinks they couldn't care less whether you've used a condom or not. This whole thing with condom usage is such a *complex issue* (my emphasis).

The men in the Christchurch study describe condoms as 'just the thing to do', 'Oh they're okay', 'more just a safety thing', 'bloody protection', 'not the same sexually', 'they are a barrier', 'a necessity', and 'cleanliness first'. In practice the men steer away from condoms during sexual activity. They do this by reducing a focus upon anal intercourse and by allowing their sexual partner to take a lead in sexual practice. As McNab et al (1999, p31) comment

This action [of not using a condom] may or may not be 'rational' in a public health construction sense, but it may well be rational in light of Green's (1995) comment that risk taking is a common feature of sexual relationships, of the wider context of gay sexual practice.

McNab et al (1999) found risk to be a feature of sexual practice when this practice is located in a wider socio-cultural context. While some of the Christchurch men reflect on becoming positive, and one man uses the 'heat of the moment' line, the reality for these men is that they have consciously moved from anal sex to other sexual practice. However, this must be qualified in terms of who is controlling the sexual practice. The men indicate that they are less likely to suggest a sexual preference and will wait for their partner to initiate an activity. This passivity is consistent with McNab et al's (1999) observations as the Christchurch men find difficulties in communication and this means agreements and negotiations around condom use is unlikely.

Overall, the practice of negotiation has changed for the men in this study and occurs during sexual practice. Two men speak of taking someone's ejaculate orally but not reciprocating. This particular practice is connected to what Warren describes as 'having more to think about' than just the physical "getting off." For Warren, sexual practice means pleasure and keeping well,

you concentrate more about keeping sort of well I suppose, is more - sort of thing. I guess which is, over rides it I guess, the sex thing, coz you've got more to think about, keeping well, than what's more important, you know having sex as keeping well, I guess, one of the main things.

Another two men speak of pleasing their partner above their own needs. Two others talk about desiring a positive partner. This would reduce issues of negotiation around safe sex.

To me, the ideal partner would be someone to have unsafe sex with, I mean that would be the goal, to find someone who was [HIV positive] like me and stay that way and have unsafe sex because I don't really like condoms, I don't like using them (John).

Negotiation for John would occur once and thus allow continued unprotected sex. It appears that within this 'ideal' sexual relationship negotiation is not revisited with any

changing sexual needs or desires but a given; that is both partners being HIV positive reduces the anxiety around transmission and John's dislike of condoms could become a feature of sexual practice.

Sexual negotiation occurs physically for these men. Overall, they do not verbally disclose their HIV status to partners and, therefore, rely on physical practice to indicate desire. Receiving but not giving ejaculate orally is a strategy employed by two men; a reduction in the desire for anal sex is current for six of the men; two are not sexually active at present and one has moved into more exotic sexual practice. This practice he explains can increase pleasure while avoiding oral and anal intercourse. Seven of the men desire a longer term partnership. This, as John highlights above, would limit negotiation to the beginning of a relationship. Fearing rejection prevents one man from being sexually active and the other two describe no physical changes to their sexual practice.

Two men move within a fringe community of shared sexual partners which exists outside of the established gay community venues. In this situation sexual practice is a physical and non-emotional experience. Non disclosure is a feature here and negotiation is not an issue for these men. One man describes how impotence has restricted his activity recently but this has been the only change he has noticed post-diagnosis. The other man has what he describes as sex partners who visit his home for sex. Again, these men are not attached to conventional gay community and given the non negotiated sexual practice, this remains a high-risk situation for HIV transmission. The practice occurs infrequently but is directed by the partner. One man comments that 'sometimes we never used condoms' and both partners engage in unprotected anal intercourse. For this man disclosure would evoke concern for his own safety as he describes this person as a long term sexual partner, an ex-jail inmate, and someone he acknowledges has no HIV knowledge. Sexual meaning is negotiated individually by these men. Sexual practice is negotiated during sexual action. However, these men remain within a risk discourse of contracting other sexually

transmitted infections, the possibility of drug resistant strains of HIV and the possibility of transmitting HIV to others.

Sexual practice, then, holds new meanings for these positive men. As discussed, the sexual satisfaction of their partner is a feature for most of the men. Desiring a longer term relationship is also a feature for some men. The tension in knowing their HIV status and not disclosing places these men in risk situations for transmission of HIV and the possibility of receiving other sexually transmitted infections.

Sexual practice for these men involves desire, action, and strategies of emotional and psychological coping. The fear of transmission to others for three men highlights the practice change stated above in receiving ejaculate orally. Safe-sex has changed the sexual landscape to reduce the transmission potential of HIV. For positive men this landscape includes a reduction in some of the activities they used to do. Warren sums this up.

A lot of things you just automatically shut down and you don't sort of do, coz it's the condom thing, sort of thing, so you come to realise that a lot of the things we may have used to do before, we don't do now, because of the safe sex thing.

#### Safe versus Unsafe - Taking Risks



The safe - unsafe binary is strongly illuminated in the interviews with the Christchurch men, with no-one using *safer* or *unsafely* diction. This may seem a minor point but when considered in relation to a sociology of risk, this can be developed into a framework useful in understanding why HIV is still being transmitted between men in 1999. Safe sex, as viewed by the men in this study, is a goal. It is framed as preferable yet experienced as difficult. For some men 'safe sex' means a different sexual practice from before sero-conversion. Peter describes sex before sero-conversion as "hot sex", indicating sex is now something else. Andrew sees safe sex

as “non sex,” while for Alister safe sex is something “everyone should do.” Ricky, like Andrew, sees safe sex equalling no sex in the most extreme definition. Ricky and Andrew are men from very different worlds. One is educated to a tertiary level, articulate, supported by friends and family, in full time work and a relationship. The other moves within a fringe community, is not gay identified, maintains an alternative health narrative and keeps HIV as a private issue. However, both men describe safe-sex as non-sex.

To a degree you can be as safe as you can but you still want to enjoy yourself and being safe as you can means having no sex. Well to me it wasn't an option. So you're better off to be safe and still have sex, see what I mean. My thing was the only way you can be completely safe is to have no sex at all (Ricky).

Social and sexual negotiations are considered through the lens of HIV. That is, HIV is the presenting issue for attachment to medical and social services. It is also a presenting issue, for the positive man, in sexual encounters.

### Taking Control

In the Christchurch study the issue of drug treatments came up as both an everyday issue and something that disrupts the men's experience. Eight of the men are or have been on some form of medication for HIV. These drugs range from Protease Inhibitors to more general antibiotics. Three of these men stopped drug treatments because, as they explained, while the drugs provide some physiological improvement to their health they simultaneously present as both reminder of HIV and discomfort in everyday life. Some of the men knew the types and brands of the drugs, while others were unable to name the drugs they had been on, or the drugs they are currently taking. One man identified the different medication through the colour of the pill.

The men who decided not to continue with treatments, against the advice of their doctor and specialist, found a level of discomfort from drug side effects. This is coupled with an emotional disruption to their everyday life. John sums up the tension inherent in taking back some control over HIV:

Oh yes it had actually worked. It had increased my CD4 count substantially and reduced my viral load to nothing. So it had worked, I gave them up because I just couldn't handle them. I thought there was no quality of life left for me anymore. I don't know what to eat. Food has and always will be a source of enjoyment. And suddenly there was no enjoyment in food anymore, I didn't know what I could eat, what I couldn't and I thought 'Oh God,' this isn't life (John).

The decision John made to stop the drugs means he can reclaim food as an enjoyable part of his life. Shane, in a similar way, sees the drugs as a reminder of HIV and therefore feels he cannot 'escape' from living with the virus. There are times, Shane says, that he feels

more switched in because I'm not disrupting my day to day life style now whereas beforehand I was up at a certain time in the morning, take drugs, feel sick for half an hour, feel like throwing up, go back to bed, cause you don't eat, because you feel so crook, you know what I mean. Now its just so much easier for me, I'm starting to have a more normal day to day routine, you know (Shane).

Side effects such as nausea and vomiting, loss of taste, impotence issues and the cost of prescriptions were all issues for these men in maintaining drug treatments. As Shane states above, the decision to stop the drugs is based on more than side effects. Presenting as "normal" for Shane is an important issue. Drugs being taken every few hours may signify HIV to others.

For two other men the drugs have been and continue to be accepted as a part of life with HIV. Both these men have older diagnoses. This may mean that the longer the term of diagnosis the more willing a man is to accept drug treatments (with all the



side effects and disruption identified above). Others in the study view drug treatments in terms of a progressing illness. Alister will take medication when his doctor advises that “he has to.” Ray explained that he has been on other medications in his life and sees the drugs in terms of being unwell. He has a narrative of ‘wellness’ and drug treatments would disrupt this. Ricky equates the drug treatments with terminal illness and final stages of life, he likens drug treatments, and the information necessary to manage them, as “going around funeral homes and picking what kind of casket you want.” This linkage between drug treatments, so often sighted in the media as life saving, is considered by Ricky as indicative of life-terminating. This is more than denial or avoidance. These examples highlight the active involvement these men have as a skill in their daily lives. Taking control, in this case with drug treatments, is contextually presented here to highlight both the agency held by the men and the tension present for them, as a decision like this may contest the advice of their health professionals.

The decisions made by the men to stop drug treatments were made for and by themselves. This responsibility is significant as it again highlights the very isolated experience HIV may mean for them. Decisions may be seen as subversive by a more dominant medical position. The implications for this ‘taking of control’ are important because these men are sexually active. That is, the men are unsure how the drugs impact on their being infectious. The men who have ceased drug treatments to present as ‘normal’ may have a drug resistant viral strain. These men are unlikely to enter into discussions with their sexual partners on viral loads or their own HIV status; therefore, risk of transmission may occur. Taking some control when living with a chronic illness is consistent with the literature (Weitz 1994). However, as HIV is sexually transmitted, the issue of control intersects with the power issues in sexual practice.

### Conclusion

In this chapter I have shown that the changing relationships these men have with social institutions produce a new range of risks for them. Firstly, I argued that an increase in social control, by the police, resulted in some of the men seeking sexual partners in alternative locales. Awareness of the police action toward other HIV positive sexually active men, and information through experiences or the media, results in reflexivity (Giddens 1991). The men incorporate this new context in terms of their HIV status and manage the risks of police action or advice from health officials.

Secondly, I argued that sexual risks are paradoxically increased in a context of increasing social control. The men follow their sexual partners' lead and in some cases unprotected sexual intercourse has occurred. The charges of other HIV positive men for unprotected and undisclosed sexual intercourse means the men here will probably not disclose their status as there is a risk they could be arrested and charged. Thirdly, I showed that active agency is an outcome of such reflexivity because three men rejected the advice of their health professionals and ceased drug treatments. This supports the thesis that the men manage their HIV condition individually and this can be seen as an outcome of their relationships in society. The context of risk for these men is the 'risk-society' which Beck (1992) posits as occurring in the contemporary industrialised world.

The HIV positive men in this study risk disclosing their HIV status. The risks now include arrest and public attention. These risks are new and, as this chapter has argued, develop within a context that Beck (1992) would argue is an outcome of a changing set of relationships between the individual and social structure. Previously I have argued that a neo-liberal system sets a context for individualism and self-monitoring. The management of the risks that emerge within this context for the HIV positive men are discussed in the next chapter.

## Chapter Five

### Findings -

### The Management of Risk

The previous chapter argued that there is a context of risk for these HIV positive men. This chapter will discuss the risk management strategies the men in this study use in their sexual and social lives, beginning with a discussion of disclosure issues. The arrests this year now place increasing pressures on positive people to disclose their HIV status, as to not do so may result in arrest. Paradoxically, to do so may result in losing control of the information and, in some cases, violence. The next section discusses how HIV related stigma is an outcome of increasing media coverage and indicative of society's anxiety around HIV issues. Beck (1992) argues such anxiety manifests into adverse reactions, in this case HIV stigma. Finally, there is discussion about the changing relationship these men have with the local gay community in Christchurch. This community developed assistance and support in HIV issues from 1983 (Lindberg et al 1996); however, the men indicate a change in how other gay men see HIV positive people today. The changes the men identify highlight new risks for these men and their sexual partners. This chapter will argue that in the management of risks, these HIV positive men paradoxically leave themselves in situations of risk and the possibility of risk for their sexual partners.

#### Disclosure

Disclosure of HIV status emerged as a major issue for the men in the Christchurch study. Disclosing, or revealing to others that they are HIV positive, is problematic for these men. There are four sub-categories in this section. The historical disclosure experiences are discussed first. This discussion is followed by the current context of

disclosure. Third, the consequences of disclosure are examined. The final section in this category focuses upon the risks in disclosing an HIV status today, as seen by the men.

### Disclosure Experiences

All of the men have disclosed their HIV status to some others. Various people were included in the diagnosis news. These included partners, friends, family and employers. One man explained he had to disclose to his boss as “it was on the medical form.” His choice in disclosure was therefore removed. Another volunteered the information to his employer as he needed time away from work when first diagnosed. For nine of the men it was important to tell someone else when they had been diagnosed HIV positive. The men selected people who they felt they knew well and trusted. However, this inclusion of another had some surprising outcomes as, for example, when Peter tried to include his family.

We’ve never really talked about it just la la la talk you know what I mean. I’m sort of saying to them, ‘what’s the story, I want to talk talk talk’ and then I want to get talk back from them, what’s the story. They just sit down and watch TV. They don’t want to talk to me.

Peter is reaching out for support while his family ignores the issue. This may be a coping mechanism for the family but his attempt to include was met with exclusion and withdrawal.

[they pulled back in a] physical way, emotional as well, they don’t talk to me. Makes me feel hurt, then I think ‘oh fuck them’ I don’t care (Peter)

The message he receives is that his family are distancing themselves from HIV and, thus, him. Other men described negative reactions from friends they disclosed to. A

number of the men found themselves in a paradoxical position of being both the person seeking support, by including others in this news, and being the person solely supporting the family member or friend. Some men clarified confusion and myths that existed while others had to get information for their friends and family. This placed pressure on the men to be able to support others while they themselves were adjusting to life with HIV.

A number of different reactions happened for these men when they disclosed their status. Sex with partners stopped for two men immediately. This reflects the sexual experiences discussed previously, when the men had a period of celibacy post diagnosis. Relationships ended in two cases with the additional stress of one partner being HIV positive.

### Context of Disclosure

The experience of disclosure frames the men's approach to disclosure today. The literature shows that disclosure and inclusion of supportive people are key issues for HIV positive people (Stein et al 1999). These men have confided their condition to at least two people. However, disclosure is contextual. Trusting a family member, friend or partner provided a level of security around disclosure. That is, the men balanced the possibility that this news would not be received well. Disclosing to others, such as new sexual partners, is a different experience for these men. Not knowing the person well means disclosure becomes a risk to be managed by the men.

There are a variety of milieu these men move within where disclosure becomes an issue and, thus, a tension for them. These include parks and other public sex spaces (beats), gay nightclubs and bars, sex on site venues (saunas), other social venues and the men's homes. The gay community in Christchurch, specifically the social and

recreational venues attended by the men, is one context where they find disclosure complex. There are three major reasons identified for this complexity. Firstly, the positive men identified the lack of control they had over the information once they had informed others. Secondly, there is a risk of violence toward the positive person. Thirdly, a fear of rejection sometimes prohibits disclosure. The gay community, as reported by these men, is a site in which support is lacking and one where further marginalisation occurs. The men overhear comments within community events and describe some of these as unsupportive toward HIV positive people.

The [gay] scene is so false and fickle, It really is. Pathetic, dizzy fucking queens. There's no compassion, they don't think 'oh shit that could happen to me one day', you know what I mean (Shane).

The perceptions formed by the men from their interaction with others frames how they negotiate sex. Shane perceives a lack of experience and knowledge for HIV negative gay men. The lack of 'compassion' Shane speaks of is noticeable to a number of the men and is perceived through verbal and non-verbal interaction.

Within the sex on site venues the culture is one of not talking, making verbal disclosure problematic. The Christchurch sex on site venue referred to by the men is a two floored space in the central city. There is a lounge area with television and coffee facilities. Also on this floor is a spa and sauna area. On the upstairs level is a large room, made into smaller rooms with the use of partitions, drums and cubicle areas. Loud music plays continuously in this upstairs area. As John states "the culture of the sauna is sex first, questions later." The men who attend this venue see it as a place for sexual contacts. Nine of the men in this study have attended sex-on-site venues. Five of the men are currently attending a sex-on-site venue in Christchurch. Responsibility for disclosure, therefore, is somewhat removed from them. As well, Peter's lack of English is an added barrier to spoken disclosure.

The men in the study who attend saunas and sex-on-site venues do not disclose their HIV status before sexual activity. One man describes how he sometimes refers to HIV during sex as a way to introduce the issue and when asked directly he will disclose. Peter explained people sometimes “might spell on their hand or something, and I may understand that.” The saunas and sex-on-site venues are darkened, creating an atmosphere, and this adds further difficulty if spelling on hands is the only disclosure method.

Disclosure is managed by the men. As discussed previously, the men are aware of the negative attitudes directed toward HIV and, thus, to them as HIV positive people.

I mean it's hard coz it makes it difficult to actually tell people. Like you feel like for some reason you might want to mention it or just let them know or whatever, you know, [because of the] sort of attitudes you think 'no, I better not' because of the negative reaction (Ray).

This man manages his non-disclosure for self protection. Ray identifies the risks in having a ‘public’ HIV status. Disclosing one’s HIV status places the HIV positive person in a position of giving up control over the information. Questions arise: will they tell anyone else? Will they reject me? Paradoxically, storying one’s HIV status may provide a context of negotiated safer sex while it can also lead to a romanticised construction of love and an unsafe encounter. Therefore, one’s decision to reveal an HIV status is more complicated than a legal or moral responsibility to do so.

Research highlights the issue that men who have sex with men do not disclose their HIV status or discuss this status in casual sexual encounters (Murphy 1999, p3). Murphy (1999) reports data from the SMASH (Sydney Men and Sexual Health) study which shows that gay men are not usually disclosing sero-status in casual sexual encounters. From the data collected in this Sydney study 32% of all gay men were told by their sexual partner of their status; only 36% revealed their sero-status, either

negative or positive (Murphy 1999). While the findings show HIV positive MSM were likely to discuss the issue of HIV if the subject came up, Murphy (1999, p4) reports “if they *don’t* talk about it then they’re much less likely to use a condom. If they do talk about it then they’re more likely to use one.”

It follows, then, that by not disclosing the status remains unknown. Thus, there is equilibrium for both sexual partners. One man spoke of sex in the park and described how he would not disclose in this setting, but would be more likely to in his home. For this man the park is a safe space in which he can keep his HIV status private, while another identifies the park as ‘the risk’. Therefore, milieu becomes central to an analysis of risk.

These men disclose to some people. They story their HIV status in terms comfortable to them. Given the reactions these men have had in prior disclosures, their hesitancy and/or refusal to disclose their status is not surprising. The men speak of losing control, risking violence, isolation and social closure by the gay community as reasons not to disclose. Now there is the possibility of arrest.

### Consequences of Disclosure

There are three consequences identified by the men in disclosing their HIV status. First, the men show that even with trusted friends and family members HIV can produce a cleavage in these relationships. A number of men indicate this taints their approach to disclosure today. The second reason, following from the first, is the threat of violence toward HIV positive people. One man spoke of being threatened for “infecting” another person, while other stories from the men include verbal abuse.



I had a bit of trouble at one stage with a guy who assaulted me [at a sex on site venue] he came up to me and he said 'you killed such and such or you murdered such and such'. The person's not even dead anyway, I mean, they've got HIV. Anyway that is what he said to me (John).

While John did not confirm his HIV status in this situation he is now aware that some people may be violent around this issue. The third reason identified in not disclosing one's HIV status is through a fear of rejection. One man noted that his needs in sex were as valid as his partners' and if he brought someone home, he felt his needs should be met sexually. Losing control of the information is an additional aspect. That is, the men fear they lose control over the information if disclosure is received negatively.

You don't know, you don't want to...sort of...besides being refused you know that you tell someone, are they going to tell someone, are they going to tell somebody else, that comes into it to (Warren)

For Warren the issue of rejection and loss of control over the information of his HIV status is a risk he negotiates by himself.

The men detailed a number of negative reactions they have had when first disclosing their HIV status. As discussed above, the positive men found themselves the sole conduit of information for others. This has resulted in some of the men facing pressures from others to provide information about HIV. This reaction accompanied some questioning about possible contraction of the virus and, in one case, an accusation that the positive man intentionally switched coffee mugs to pass on HIV. The man's guest, another gay man, has not retained contact. Each of these reactions, physical and emotional, have left these men with an impression of the consequences of disclosure. While some family members provide a sole sense of support and continued financial and emotional help, these initial reactions to telling others have left the positive men with a cautious outlook toward disclosing.

This can be highlighted with the support group meetings held monthly in Christchurch. While this group is primarily a social get-together, some of the men see meeting with the group as disclosure by attendance. This tension between the desire for support and understanding by other HIV positive people and having to disclose is summed up by Warren. He was asked about the support areas for HIV positive people in Christchurch.

No, I've never got involved in any of those social HIV group get togethers, like [the social group] you mean something like that, no, there's this thing like who are you going to bump into and who's going to say what about you to anybody or whatever then it all comes down to being treated differently, and sort of...you know pointing the finger and telling everyone, you know how it goes through the chain. So I've never got involved deliberately because of that sort of situation (Warren).

The central tension in disclosure is presented here as Warren talks about potentially negative outcomes. For Warren this negativity may manifest in becoming the subject of gossip around his status and being treated differently by other HIV positive people. Pressure is added with the police prosecuting HIV positive people for retrospective sexual acts.

Responsibility for disclosure of one's HIV status is sometimes shifted by the positive man to others. This strategy is employed by some of the men as an invitation toward disclosure, while others use it as a way to simply shift the responsibility of taking a lead in approaching the issue. For Ray, this means that when he is helping with community HIV events he is disclosing something. For Murry, leaving literature that he obtains from the New Zealand AIDS Foundation, around in his flat is disclosing. For Bruce, 'disclosing' occurs in his home as he leaves medications and hospital appointments in the kitchen. Ricky, in refusing to do certain sexual acts, like unprotected anal intercourse, is signalling boundaries around sex without detailing why this activity is ruled out. This refusal occurs without verbally announcing his HIV status. Each of the men is employing ways to partially disclose and is managing

the information. They manage the process of disclosing by reflecting on past experiences of disclosing and moving some way along a disclosure continuum. This management creates a tension in sexual action as they have the information and are aware of how this may be received. Therefore, decisions are made by the men to not disclose before sexual action.

### Disclosure as Risk

In disclosing their status the men are involved in managing risk. They risk rejection, losing control over the information, relationship breakdowns, family pressures, insurance loss, possible violence and the possibility of arrest. Decisions around disclosure are made in terms of assessing the audience or situation and possible consequences. The men have experienced negativity through disclosing their HIV status. They are also aware of the attitudes held by some HIV negative people; therefore they manage the risk of a negative experience by not disclosing.

Those who employ a cancer narrative or heart problem story can disclose being unwell. They can talk to others about this. However, discussion is only up to a point. The discussion of sexual functioning, sexual action and desire is not a feature of our society. Given the fear of rejection, loss of control over information, possible aggression and violence directed toward these men, they manage the risks in disclosure. Support by other positive people can be gained through disclosure. However, in daily life this is mediated through a context of negative attitudes by others toward HIV and those infected. Some of these men avoid all contact with other positive people for this reason. They risk being identified.

So you have to be careful who you give the information out to, that they are going to use it in the right way, that they are not going to tell all and sundry (John).

## Stigma

Stigma is an issue for these men. As discussed, disclosing risks losing control of the information and possible stigma. As with disclosure the men manage stigma in their everyday lives and in their social and sexual negotiation. There are three sub-categories within this section on stigma; context, management strategies and the outcomes and responses for the men in this management of stigma. One man describes how he sees the attitudes of others toward him as a sexually active man.

Just the feeling, I suppose, that because you are being told that you're positive, probably society I suppose, the way we feel as though, a bit of each personally, and society wise that um, just because you're infected you shouldn't be having sex at all (Warren)

### Context

One man feels stigmatised when dealing with Work and Income New Zealand. He comments that "I get that impression every time I go and see [my case worker]. He thinks it's a fake. His theory is if he's got AIDS it's his own bloody fault. He should suffer himself." Andrew's impressions of his case worker are subjective yet, none the less, a real experience for him. The impression he refers to restricts and inhibits his ongoing relationship with WINZ.

[The case worker] always gives me a funny look when I walk in there and blah blah blah and more or less tells me what the fuck do you want now? I don't like his attitude (Andrew).

The immediacy of HIV related stigma is highlighted by Ricky as he describes how he felt when he was first diagnosed:

It's a huge stigma, I still remember when I was first diagnosed I felt as though I had this huge 'A' tattooed on my head as soon as I walked out of hospital...I just really did feel there was this really big 'A', but that's partly my own perception but then its certainly the community's.

This perception mirrors Shane's experience indicating stigma is still a major issue for people living with HIV today. Stigma can be attributed to the men simply by their attending an AIDS Foundation office. For example, Shane visited the local office of the New Zealand AIDS Foundation office when he was diagnosed and it was "awful, awful I just hated it. I hated it, to me it was just - I just found the whole thing really humiliating, you know." For Shane, going into the office is saying 'I am Positive.' This view is supported by Ray.

Someone sees you, oh you must be positive because you've gone to that AIDS Foundation building. I saw you walking in, yeah there's all those sort of issues.

Hospitals, clinics and AIDS Foundation offices are sites of support as well as possible sources of stigma for the men. This contradiction is a tension for the men as they all attend out-patient clinics at the hospital. A heterosexually identifying man explains that he has additional stigma in that assumptions are made about his sexuality and drug use history. Health workers have passed comments to him about the size of his veins, inferring he was an intravenous user. This man manages this by narrating his infection story to staff. A number of men experienced being asked about how they became infected. Given their disclosure experiences and negative reactions the men use narratives constructed around infection to counter, and thus manage, the stigma they perceive. Shane highlights this negativity as he describes a visit to a local gay bar.

I was in this bar and um, I didn't even know this guy from a bar of soap, and um I said 'giddy, how are you' and he said 'you've got AIDS, you've got AIDS' and I said 'fuck off' I said 'I haven't got AIDS' and I said 'who the fuck are you to speak to me like that you cunt', I said 'fuck off', that was a complete stranger, I thought who the fuck are you to speak to me like that and um that's why I'm not on the scene, that's why I don't even go to gay bars.

The outcome of this experience for Shane is one of further isolation as the gay 'scene' has become a site of potential hostility. He did not know the man and, therefore, takes a risk entering a gay bar that this situation may repeat itself. For Shane, the decision to not return to the bar is made. He is denied the option of disclosing himself, as the information is known and then used as a weapon toward him. As this confrontation takes place in a public bar others overhear.

One of the negative pressures identified in living in a smaller city like Christchurch is homophobia. The men in this study indicate there is a relationship between homophobia and reactions from other gay people toward HIV. Homophobia, the fear of homosexuality, translates into a difficulty in being open about sexuality issues and for these men this extends into disclosure issues of their HIV status. Shane comments,

well it seems to me overseas it's more open. How many men do you see holding each others hand walking down Colombo St in Christchurch? You can't because some bastard will punch you in the fucking head, simple as that, and you fucking lay in hospital for a week.

Shane's comments highlight the extent to which homophobia may manifest in violence. For him, this dislike of homosexuality can be present in gay venues and other gay people.

you go to a bar here and everyone will sit there like this and they're not even hardly speaking to each other. They don't know how to converse with each other because with all this stigma out on the street of being a faggot so to speak, so they get in there and they still won't relax, they still won't open up in themselves.

Shane highlights how and why homophobia exist within the gay community. Other men note that 'secrecy' and 'ignorance' are features of homophobia. These words are used to describe the relationship between the general community and gay men.

### Management of Stigma

A number of men indicate that there is a problem within the gay community as stigma is an outcome of attitudes by others toward them as positive people. This can result in social isolation.

I know for a fact that there's a lot of men out there that won't go to anything, because they are too frightened to go, they're trying to cope with what they're dealing with at the time or whatever (Shane).

Social isolation is one outcome of HIV related stigma. This man comments that HIV positive men are avoiding the commercial gay community because of HIV related stigma. Stigma extends for some of these men into their sexual relationships. John articulates the way stigma operates as a pressure issue in his sexual life.

I've heard it said 'oh HIV positive people shouldn't be allowed in the saunas' but when you're saying that really what you are saying is HIV positive people should be shot.

To manage this stigma John passes as normal. HIV is masked physically and managed emotionally because disclosure is avoided. Other strategies include avoiding other positive people, as in support groups, and attending hospital appointments very early or very late in the day.

I make my appointment for the last one of the day because (a) I don't want it to interfere with work, and (b) hopefully I'm the last and don't need to go through that [seeing anyone I know] (Ricky).

The 'going through that' is in relation to seeing other people at open out-patient clinics. This strategy again supports the position that the Christchurch men are individually innovative in managing the social tensions connected to having an HIV diagnosis. Managing the information of being positive means avoiding some places, groups and activities. Thus, by not being in an HIV positive space, the person cannot receive stigma by association (Goffman 1963).

### Responses to Stigma

The men see the potential in a supportive gay community to reduce stigma and allow disclosure. However this situation would mean visibility as HIV positive people. The men overwhelmingly present as normal. They pass at this time because they do not appear as stereotypically HIV positive. None of the men have signifying aspects of HIV. In later infection this can include noticeable skin cancers. However, at this time social isolation is an outcome of stigma for some men. One man is not seeking work because he believes he was fired from a previous job and this will occur again because of his HIV status. Isolation will mean HIV is less visible in society. A lack of visibility means little challenge to existing social attitudes within and outside of the gay community. Beck (1992) would argue that this anxiety toward HIV may precipitate a social movement; however, the men here individually manage the risks they identify. One outcome of the current context is an increase in isolation from other HIV positive people.



I've also heard of negative stuff, not directed at me but other people I know who are positive. People will talk to other people about it you know, 'such and such is positive', but you can tell by the tone that it's a negative thing like avoid that person kind of thing. It's not supportive, yeah, in some ways the gay community's a joke because it's not a community, like it doesn't have a welcoming feel. In some ways it's like the wider community (Ray).

### The Local Gay Community

The gay community has long been a site of support and education for HIV and AIDS issues. The New Zealand AIDS Foundation has worked in a community development role within the gay communities in New Zealand's major centres. For HIV positive gay men belonging to, or having a sense of connection with, the gay community can provide meaning (Brotherton 1997). 'Community' can be seen as more than a fixed geographical location and as a symbolic belonging. However, the international literature shows that stigmatisation of positive men occurs within the gay community as well as outside of it (Brotherton 1997).

### Community Education

The gay press has continued to be a forum for community education of HIV issues. The education work done in New Zealand is targeted. Community messages are produced by the New Zealand AIDS Foundation to educate men who have sex with men. These national campaigns take on various forms and are mediated through the gay community in media, poster and printed formats. The men in this study have "noticed them" and largely see the messages as "good." However, as John states "I don't take any notice of them." Ray says he saw a recent poster called "love safely or

something,” while other men said they have either not seen any posters or only noticed them.

One recent campaign registered with some of the men. The Bottom Line campaign was designed to challenge assumptions made by sexual partners toward the HIV status of their partner. Alister explains,

it's like, there's a poster somewhere, yeah it's that one there - 'he didn't use a condom, he must be negative like me, he didn't ask me to use a condom, he must be positive like me.' It's like see people just take for granted that...

Tony: Does that work for you, being a positive person?

Alister: How do you mean?

Tony: When you meet someone do you assume they are positive?

Alister: No, no I just assume they're negative anyway.

The poster aims to challenge men who assume their HIV status is the same as their sexual partners. A number of men in this study, including Alister, make an assumption that their sexual partner is HIV negative. This is a risk management strategy. Other men described education as part of the gay community.

Well most places will have some sort of like media like posters or brochures or the gay press at gay venues, makes you think about, like condom campaigns, those posters of safe-sex in the toilet, that sort of stuff, but beyond that, that's about it really (Ray).

Ray captures the notion of education as part of the community however he sees it as just that. There is no engagement with the issues of the content, style or medium of the material. Another man is unable to connect these aspects to his experience and sees the posters, brochures and gay press as 'just being there.' He does not explain what it is he 'thinks about,' but it seems clear he understands this education is a feature in gay venues.

### Alternative Communities

For the Christchurch men the local gay community is not one of support but a site of hostility. Worth et al (forthcoming), report a finding from the Male Call data that HIV positive gay identified men are more likely to be gay community attached than HIV negative gay men. This may mean that in not disclosing the positive man can pass as normal, as 'just being a gay man,' and not as an HIV positive gay man. The Christchurch study finds that the gay community is not supportive or welcoming of HIV positive people, as John observes.

On the scene HIV is a dirty word...I think it needs to be a lot more acceptable for people to tell other people they have got the virus and not be ostracised or made to feel bad about it. And then I think you would find a lot more HIV positive people would be divulging the fact to their sex partners.

While the men largely find the gay community a negative milieu for HIV positive people, Ricky did identify value in a community that sets norms and mores around behaviour, in this case safe sex.

There is still those people coming out that haven't got that inner strength and still need to cling to that collective group, and I think that's where the gay community has still got to be there, to actually provide that collective group for those people still going through that (Ricky).

The Christchurch gay community is a milieu within which some of the men in the Christchurch study socialise and seek sexual partners. Andrew's dislike for the gay community reflects Shane's earlier experiences. Andrew regards the gay community as a 'site of infection', somewhere to 'catch sexually transmitted diseases.' Two other men see the gay community as the 'least supportive' area toward HIV, and for one this limits his contact with it.

When it comes down to support I think the gay community in general is one of the least supportive environments in the country, generally I think it is ... I'd probably like to be a bit more involved maybe, but the only way that I would probably be involved is through my being HIV, and I'm still quite wary of that in Christchurch (Bruce).

The cautiousness Bruce describes inhibits his involvement yet he identifies that being HIV positive can be used within the gay community to educate others. Beck (1992) would suggest that this caution is consistent with a risk society in that HIV negative men may be managing the anxiety of possible HIV infection. In this way, the marginalisation of HIV positive people may manifest in the way Bruce describes. Engaging in sexual practice may present anxiety for some men who have sex with men; gay men might resist safer sex messages because they can be read as oppressive (McKirnan et al 1996). In arguing that there may be a desire to escape the cognitive norms and understandings within a gay community McKirnan et al (1996) find risk to be more complex than a rational process. Another man views the gay community as a place of non-trust.

I don't like all the shit and everything else that goes round in the gay community. You go in there with a partner and by the end of the day you won't have your partner very long. If you want to catch any disease that's a good place to go (Andrew)

An alternative local fringe community operates for Andrew to move within. This is not seen by the men as a 'gay community,' but as a series of social get togethers in private houses where prospective sexual partners are met. This is a private milieu and somewhere conventional HIV education is not operating. This fringe community works on a sharing of sexual partners, as Murry explains:

[it is] quite easy to approach it. Another friend of mine, younger than I am, he likes younger people and sometimes he'll bring them around to me. Well most of them, well I've got to know most of them after a while. There're a few, I only see them for sex. Apart from that I don't see them.

This fringe community is one area where sex happens, but in the absence of norms and mores of safe sex and discussion of HIV. Stigma is managed because sexual practice is the only issue in common. The negative reactions from the conventional gay community drive a number of the men away from nightclubs and sex venues. Stigma is not an issue in the fringe milieu because the men explain their health problems through stories of a 'bad heart' or 'cancer.' Disclosure is not a feature in this milieu.

Within both the conventional gay community and fringe areas, the tension of disclosure and possible stigma is weighed up by the men. Comfort in alternative narratives reduces the stress from disclosure pressure for some men, but may place others at risk. For those who are sexually active the desire for their partner to be sexually satisfied exceeds their own.

Six men desire an emotional and sexual relationship from within the conventional gay community. Two others move within the fringe group. Two men desire another HIV positive partner as this would reduce negotiation to the first sexual encounter. Sexual fantasy for one man centres his desire on another positive person. Hence, desire is a feature within their sexual practice. In the absence of negotiation, desire for sexual practice places these men and their partners in situations of risk.

I think if I met a spunky young guy who was HIV positive that would be wonderful because everything would be fine, and like you could have a relationship where you both knew where you were and you wouldn't have to worry so much about condoms. I mean you could still use them but I don't really think you need to. As long as you don't sort of cum up each other (John).

The men who see themselves as attached to the gay community, like John, do so as gay men. John's desire for another positive man develops in a milieu in which he as a positive man is aware of the negativity toward HIV. In such a situation HIV would be 'absent' from John's sexual relationship. In other words, he could be a sexual partner in a more equal relationship. His desire does not include the disclosing of his

status. There is an understanding that they both would have this knowledge. This desire for relationships, intimacy and avoidance of HIV as an issue reflects the attitudes perceived by the men toward HIV from within the gay community.

### Conclusion

Beck's (1992) risk society thesis argues that risks are produced in our modern society along with the production of goods. As such, risk is central to a modern age. This chapter has argued that risks are managed by these ten HIV positive men to reduce the anxiety Beck (1992) identifies as a feature of modern life. There are a number of risks for these HIV positive men and their sexual partners. The men manage the risks associated with an HIV identity by not disclosing this to their partners. This management is complicated by a legal context that now mandates the men to do this. Paradoxically, to disclose presents new risks of violence and social isolation. The men, through what Giddens (1991) would argue is a reflexive process, consider these aspects and manage the risks for and by themselves.

The thesis here is that a paradox occurs in the increasing of controls and mandates for these men. Controls can be both formal and informal; the police and members of the gay community operate forms of control and regulation toward these HIV positive men. Such a paradox results in non-disclosures, risks of sexually transmitted infections, the possibility of unprotected sex and thus, the risk of transmission of HIV. The responsibilities to self-monitor the HIV virus occur in a context these men are aware of. This is a context of negativity toward HIV. Beck and Giddens would argue that this negativity occurs because of anxiety within a risk society.

## Chapter 6

### Summary and Discussion

Well, risk for me, the most severe risk for me is there is no risk I reckon. The only risk is that I might get a strain of the virus that was more dangerous. Well that's probably more likely from somebody who is already positive anyway and someone I'd probably meet at the sauna so yeah, you can pretty well eliminate the risk by being pretty selective about your partners (John).

As I have shown in this study, the experiences defined and articulated by the men exist within a context of increasing regulation and control for HIV positive people. Sexual and social negotiation operate within this context and are features of these men's lives. Risk is an aspect of this negotiation process. As John comments risks are individualised, something he manages in his sexual life. This thesis has argued that such an individualised view of risk occurs in a context of increasing regulation and control.

In addition to increasing the developing literature about HIV/ AIDS in New Zealand, this study illuminates the living experience for these men. The men in the Christchurch study have lived with HIV for varying lengths of time. However, length of diagnosis does not translate into comfort in sexual and social negotiation. The man diagnosed in 1986 faces the same tensions in sexual action that the men diagnosed in 1997 face.

This study took place in May 1999 in Christchurch, New Zealand. Ten HIV positive men who were or are sexually active with men were interviewed using a semi-structured format. A sociological view toward this lived experience considers the relationships between persons in context. This consideration includes a temporal dimension to this experience. Because HIV is a dynamic condition, often manifesting

late after diagnosis, the social aspects intersect within and alongside of a bio-medical discourse. This chapter will summarise and discuss the findings from this research. Three identified social tensions emerged for the men in this study. Applications of these findings and further areas of research are suggested. This chapter concludes the thesis and synthesises the argument that an individualisation of HIV risk has a paradoxical outcome for these ten men and their sexual partners.

### Social Tensions

The first tension present for these men is social pressure. This pressure is both societal and internal. For example, disclosing one's HIV status is a tension that develops from a gay community's expectations that a positive person will disclose. The literature shows negative people assume their partner is negative unless told otherwise (Fisher et al 1998). Tension is produced given that these men overall do not disclose their status. There is a struggle for some of the men in terms of when to disclose. Some men talked of wanting to include their partner, but struggled with the tension of when this was to be done. One man commented that if he disclosed to a partner and the relationship ended after six months the partner would still be free to tell others. Not disclosing means keeping this information back from the sexual negotiation. Risk is managed in this process.

Pressure to take and manage drug treatments is resisted by three men. Other men are aware of recent bio-medical advancements and one man comments that he would take drugs when told he has to. The media presents advancements in treatment as life saving and health improving. One man sees the drugs as a step closer to death. Managing the pressures to stay well is a feature for the men; for example, some are advised to eat certain foods but do not have the money to buy them. Being asked about infection by health workers, or in one case having assumptions being made



about infection, produces responses by the men involved. Some of these responses involve alternative narratives of illness.

Pressure not to have sex is also a feature for the sexually active men. Being aware of the attitudes toward sexually active positive men sets a context for tension.

It's being diagnosed with it sort of, for a long time I didn't have sex coz you know, you sort of feel as though you're infected so you shouldn't sort of, until you get used to it. You know, sort of infectious so you feel as though you shouldn't be having sex for a while until you get accustomed to it and. A lot of other people don't feel as though you should be having sex either I guess. You know, people in general (Warren)

Warren captures the tension between balancing his needs and societal expectations of positive people. There was a delay between diagnosis and resuming sexual practice for him and the other men. Warren also exemplifies the current situation when he comments that 'people don't feel as though you should be having sex'. Being sexually active and aware of this social perception produces a tension.

One man stated that his sexual needs are as important as his partners.' The risks taken in sexual practice place some of the positive men at risk of other sexually transmitted infections. The attitudes of others toward HIV places pressure on the sexually active men not to inform their partner of their positive status.

More blame can be put on you, like the responsibility of that, you oughta be more careful, everyone's basically careful but you've got to be a bit more careful, we're all equal but some are more equal kind of thing, but the disease is the reality of the situation (Ray).

The tension here is that the positive man, in meeting his sexual needs, feels a responsibility toward informing his partner. However, as Ray explains, he will be held accountable if he infects someone else. Managing the risks of being named and the possibility of arrest results in less disclosure, increased isolation and an individually managed life for these HIV positive men.

Living with uncertainty is the second tension for these men. These men are within a medical and social system of health. Living with a virus that in most cases leads to a shortened life expectancy provides a tension in the way a medical system constructs their 'illness'. The men described blood monitoring and, in some cases, not being included in what this might mean. As Andrew describes, "they just want to see if it's up any more than it was or down any more than it is." Andrew captures the tension of being within a medical system while at the same time, grounded in the here and now of life with a chronic illness. Medical staff become 'they,' while a complex set of blood readings becomes 'it.' Time is paradoxical for him when he describes the process as checking to see the changes from being "up any more than it was or down any more than it is." The past is simultaneous with the present and the virus is externalised from Andrew's experience.

Not knowing what may be happening within the body, while presenting the self as unified is also a tension evident in the experiences of the men. One man described life as "hectic" in that he could not tell what sort of day he may have. For him this unknown aspect of life with HIV means an ongoing tension for planning:

I really want to know what's going to happen, as time goes on. What happens and I don't seem to be getting to know anything that's going to come. Do you have to wait three months, nine years or something like that? (Murry)

For this man time is a source of tension. He floats polar possibilities of time and thus a difficulty in planning. The grounding of the men to narratives of the everyday is evident in this quote from Murry.

Is it going to be five years, ten years or two days or I could die of something else, which I've already been told, I could quite easily die of something else.

Some men are concerned about the possibility of physical changes to their bodies which could indicate to others that they may be HIV positive. One man called this “the progressing” and others referred to media images of people ‘looking’ ill from AIDS.

You see in programmes and films and that, it looks really horrible...really loose skin, with great big dark blotches on their face, the skin and arms. You think of those things of course, possible that it may happen one day. It’s just a sort of thing that you sort of think of which is a possibility of course if you get so ill that it may happen, possibly being optimistic that it won’t (Warren).

The men are not sure what may happen. Warren is optimistic that things will remain the same. The media and popular culture provide a disturbing possibility for him as the image of ‘loose skin and dark blotches’ is a powerful reminder to self and others that one has HIV/AIDS. Some of the men have questions about how the treatments may be working for them. Not knowing what the treatments may be doing to viral loads leaves questions open to be interpreted and then self-answered.

Oh people that are positive and they’ve got no sort of...They’ve got a good CD4 count and they’re undetectable viral loads and they think they’re not, they think they’re safe having unsafe sex because they’re not able to pass it on (Warren).

In practice, the option of unsafe sex is taken up as the positive person sees themselves as not infectious; that is, of having a low viral load. It is the unknown aspects that are defined by the positive person in order to get on with their life. As Warren states, this HIV positive person individually assesses the risks of transmission because the person ‘thinks they’re not infectious’. The tension of not knowing is overcome because a decision is made. This places both sexual partners at risk of HIV transmission and other sexually transmitted infections. Sexual practice is defined in light of this unknownness by the men. For example, one man considers unprotected ‘fisting’ (the placing of one’s hand inside the anus of a partner) as safe sex. Two men define safe

sex as “no sex.” These definitions show that safe-sex guidelines are interpreted by people in multiple ways.

There are other unknown aspects to life today for these men. They do not know whether they will meet a partner who can understand and support them. Neither do they know whether they will be accepted by friends and family members (who may have distanced themselves) or if they will work again. In one case, there is an absence of knowledge about who else is HIV positive. That is, one man distances himself from other HIV positive people because associating with such people means disclosure of his own status. The tension for him rests in his desire to know others with the virus (and potentially learn about their lives) and his concerns about disclosing.

Living longer with HIV on a limited income means choices are restricted. A lack of money means a quieter life for some men. For others, money represents security for the unexpected. Eight of the men are currently on Work and Income Support benefits and the remaining two work full time. Additional costs involved with HIV include prescription charges, non-subsidised additional treatments, special foods, alternative treatments (including massage) and transport to various appointments. HIV can also mean limited paid work options because of periods of illness. One man commented that recommending additional foods for HIV positive people could ignore the actual financial reality they live with.

It's all very well saying if you've got HIV you should eat these foods but if you've only got \$20 to spend on food you can't get all that (John).

For other men a limited budget restricts sports activities and social events. One recent Australian study finds poverty to be a major issue for people with HIV (Ezzy et al 1998); the authors conclude that people leave work to improve their health and wellbeing. However, a reduced income means less access to the social activities they

are involved with. The Christchurch study is consistent with Ezzy et al (1998) in that living on a benefit means a restricted social life, as Shane points out.

That's been a big adjustment in my life to cope with as well. That would have been one of the hardest things I had to cope with as well, financially that has been really difficult for me. I can't afford to go to those clubs anyway half the time, I just can't afford it.

The social and medical aspects of life with HIV co-exist for these men. Shane comments that his life on a limited income adds pressure, yet this occurs because he has HIV. The treatment advancements mean that as people live longer, they will face these everyday life issues like financial pressure.

The unknown aspects of life with HIV ground the men into an everyday of the 'here and now'. The men talk of 'monitoring levels' (of viral replication) and feeling 'as though I'm coping.' The reminders of being HIV positive come through the 'monitoring' and 'feeling healthy.' A sense of waiting for something to develop is the issue that grounds the men into the 'here and now' they describe. The diagnosis date is significant for a number of men and, as John describes, a life-changing event:

but when you get HIV you suddenly realise that maybe your place in the world is not going to be there forever. You question it.

The paradox of 'feeling well' and living with a virus (that so often leads to a premature death) means that these men have hope for treatment advances, knowing there is a possibility that they may become unwell. One man described himself as 'fortunate' in staying well. The expectation that something may happen is countered in the news of treatment advances. Alister captures this experience:

yeah, sometimes I feel quite like something's about to happen and I just feel all weird and that and nothing ever happens, it's just me feel[ing] chronic like that.

The experience of waiting for changes in health is a feature for all of the men, regardless of how long ago they were diagnosed.

Knowledge is one important aspect of making sense of the everyday reality of living with HIV. The men have a continuum of knowledge around HIV issues with nine indicating they see information and knowledge as important in their gaining a sense of control over HIV. However, as previously discussed the men accept information from health workers passively. The final man relies on his doctor to provide him with an analysis of his current situation.

A connection between knowledge and comfort in sexual behaviour is noted in the research. The men who feel more comfortable sexually are those who indicate a sound knowledge base around transmission of the virus. The men gained knowledge through printed format, Internet, health workers and counselling sessions. The men express an interest in wanting to know what is going on. Warren is typical in his view:

I want to know what is going on, I feel it is, it's important to know what's going on...it's sort of following up what they tell you

Warren indicates that the information is delivered to him by health workers and he follows it up at the library "just to sort of get confirmation that what they're saying is sort of, you know." Other men wait to be told.

They don't tell me, they just look at the chart themselves and that's it. He just gets the result, has a look at them and bang that's it and tells me I can go home now, doesn't tell me anything about the test results or anything (Andrew).

Andrew's position as patient is reinforced in the above example. As such he waits for the 'expert' to advise him of the results. The perception of being distanced from the

information results in Andrew seeing himself outside of the system supposedly there to help him. He feels isolated and left out of the interaction. This paradox, of being within the system yet feeling of outside of it, is exemplified by Alister, 'when he says,

well the doctor doesn't like, coz I see that doctor there [Infectious Disease Specialist] and he doesn't refer back to that doctor [GP] and then I see him in six months time and so I don't really know what goes on with anything eh, I'm just like a little floater that just floats along between, 'here you go, here you go'.

Alister held up his arm at this point, indicating that his vein is the focus for the medical system. This response is consistent with other men when they describe how the medical system can leave them feeling outside of the process. Andrew explains how he feels that he wants to 'go through this alone' while others indicate a choice to not involve others.

Some men have changed doctors and some have accessed library and Internet information. However, all remain the main source of information for the significant people in their lives. This places pressure on the men to be both recipient of information from a system, while simultaneously interpreting this information for family, friends and supporting people. This conduit system of information exchange places pressure on the positive person to both understand and accept their condition. Strategies around this conduit mean the person with HIV can distance others or provide selected information.

What happens is my mother really asks me how I am usually. Like if I go to the Specialist she'll say 'how did you get on at the Specialist' and I mention that something has come up, but if there is nothing to worry about I just say 'there's nothing to worry about at the moment' because I don't want to live my life worrying and in fear (John).

John controls his mother's interest by his coping strategy of not getting into details about the appointment. This interchange again highlights the person with HIV as a

source of information to their family and friends. Being the sole conduit of information for others places the men in a position whereby they can involve, express or minimise the situation.

The third tension is social closure from the gay community against known HIV positive men. While one man no longer associates with the gay community in any form, the other nine move within or on the fringe of the gay community in Christchurch. This association may be in the form of gay friends who move within venues and include the men vicariously, or the men select sex-on-site venues as social areas. These men have described the hostility they experience within the gay community and, thus, they manage disclosure and social relationships accordingly. For some of the men avoiding nightclubs reduces the possibility of hostility, while others select only sex venues where talking is not a feature. The tension between HIV positive men identifying as gay and their experiences of hostility from the gay community results in a fractured experience for some of the men.

You hear how some people bitch on, you overhear conversations 'well so and so, is he positive', and God what the fuck are they doing up here [in a sex-on-site venue] and that negativity really saddens me, and I go 'oh thank God they don't know about me. You know, well I honestly don't know if I could stand up to that. I guarantee I couldn't stand up to the latest thing in the newspaper. I mean that would absolutely devastate [me] (Ricky).

For this man the negativity he hears from people in this gay venue means he is less likely to disclose his status. In terms of his negotiation of sex he is not likely to inform the other person of his HIV status. This negativity highlights the closure by gay people to those with the virus. Such social closure produces a culture of exclusion. As such, the risk of others knowing is managed privately. The concern about others knowing and reacting negatively extends to the media constructions of HIV, as Ricky indicates above.



The media has a role in the production of risk definitions. Television and news coverage of the arrests in Christchurch employed expert opinion to back up the position taken by the media. Such opinion, Tulloch et al (1997) argue would assist in the construction of popular understandings of risk. As the positive men view and consume these messages so to do HIV negative people and this may explain the negativity experienced by some of the positive men in gay community venues.

The dominant discourses on risk, reflexivity and health tend to privilege the notions of the rational actor, the mind in full control of the body (Tulloch et al 1997, p222).

The pervasiveness of the media coverage was felt by Peter who does not speak English. For this man the connection between arrests, HIV and police means a locale change from seeking sex in the park to sex-on-site venues. The opportunity to engage in unprotected sex in such locales is confirmed by the other men. If the sexual partner at these venues is unaware of HIV as an issue - and if introducing condoms and safe sex for the positive man is problematic because of the events this year - the result is an increase in risk for both positive and negative men. The risks for the positive man are that they may be accused of infecting another person. The risks for the negative man are infection through unprotected sex.

Lupton (1994, p31) argues health promotion operates to govern the “self control and self-discipline over the body, both within and without the work place.” In arguing that the containment of illness and disease is not a recent phenomenon, Lupton (1994) suggests containment of the diseased body serve two functions in our society. Firstly, the diseased body is removed, thus protecting the uninfected body. Secondly, the public health message of rational behaviour (that is that the individual must exercise restraint and self-control over the body) is echoed. For the HIV positive men, the response of media statements by judges and increasing surveillance by police is to reduce the possibility of disclosure, and thus manage a new set of risks.

The construction of 'at risk' is developed in media reporting and, as coverage of the arrests in Christchurch have shown, result in the positive men internalising risk definitions for themselves in ways that may result in higher risk sexual activity. Managing the HIV body (that is to keep HIV private because of the new risks of surveillance and identification as the 'infecter') may result in the positive man removing all signals of HIV from sexual practice. For John and Shane, who dislike using condoms, this may mean an avoidance of condoms altogether. For Murry and Andrew, who move in a fringe sexual community, the introduction of condoms for sex seems more remote.

Other men are socially closed from social activities. One man stopped playing rugby as he thought he would have to address his HIV status because of the risk to others. Other men avoid the HIV positive support group meetings. They explain they have no control over who will know their status, and given the fear of others finding out, they distance themselves from the group. One man believes he is closed out of the work force. He explained he was fired because of being HIV positive. Challenging this for him means disclosing his status and identifying as an HIV positive person. This man has decided being closed out of the work force is the result of someone becoming HIV positive.

Nine of the men currently move within the local gay community or fringe areas and pass as regular, everyday (read HIV negative) people. They are both inside the community, as gay men, and paradoxically outside, because they live with HIV. They are aware of the attitudes and perceptions of others toward HIV. At times the men mask their HIV status for their sexual partners. As Murry explains "its usually the heart I tell em." This is more than a distortion for him. The narrative becomes his understanding and a way to tell others that there is a health concern. Cancer, heart conditions, and 'blood problems' ascribe the health issue within the body. That is, blood is constructed as the site of illness, not semen or sexual fluids. Living with HIV is dynamic in terms of the social experiences the men in this study consider relevant to

them. Being sexually active while living with HIV means a different experience for these men from when they were HIV negative.

### A Sociology of Risk

In arguing that changes in the relationships between the positive men and the social institutions around them results in the production of risk (Beck 1992) this thesis has suggested these changes impact on both the positive man and their sexual partners. As outlined in Chapter Two, risks are a feature of our contemporary time. As a society we are aware, via the expert discourse, that risks exists. We manage personal risk and rely on experts to manage global and external risks. Increasing anxiety in contemporary society is managed through the identification and remedy of risk. Neo-liberalist approaches to health management place increasing pressure on the individual to self-regulate and monitor lifestyle choices. HIV, it has been argued here, is an issue for our society and something that is increasingly positioned as a rational outcome of action or behaviour.

For the ten HIV positive men in this study there are an increasing number of new risks emerging for them. The introduction of new treatments means there are a set of risks around managing the medications. For instance, taking the drugs on time, taking some with food, some without, is coupled with an expectation that the men can and do manage these medications and the side effects. A decision to cease treatment is made independently of medical advice and runs counter to health recommendations for three of the men. These three men risk future compliance issues as the virus may mutate and become drug resistance in the future (Mellors 1998). However, the decision to cease medication highlights the reflexivity of these men.

The risk of being identified as an 'infector' of someone else has increased this year due to the arrests of four men for failing to disclose their HIV status prior to

unprotected sexual intercourse. Through the management of this risk the men in this study reduce disclosure of their status and for two an alternative fringe community for sex provides an environment removed from conventional safe-sex norms. Risk is paradoxically increased in this milieu as HIV is absent from sexual negotiation. Alternative narratives explain illness. Giddens (1991) argues this is a re-embedding into alternative contexts and is a result of managing the social anxiety concomitant with a risk society.

A number of changes occurring in social institutions impact on risk for these men and their partners. As discussed fringe milieus offer alternatives to conventional gay community venues, where a number of men identified negative and stigmatising reactions to them as HIV positive men. An increase in police surveillance of parks or known 'beats', where the police monitor men seeking sex with other men, operates as control for the men. Alternative sex-on-site venues are selected at times; however there is an entry charge and on a limited budget this is not always a possibility. There is a risk of arrest, identification and again being signalled as 'an infector.' This is managed by an overwhelming avoidance of other HIV positive people.

Media coverage has situated HIV in terms of the 'infectious body' and reported the mechanisms in place to contain the virus. The media also covered the interpretation of the Crimes Act (1961) by The New Zealand AIDS Foundation. The men in this study, in not disclosing their HIV status prior to certain sexual acts are deemed to be committing an offence under the s145 of the Crimes Act (1961). This situation has implications about who is identified as a victim and who remains the offender. The media constructs the HIV positive person as infector while their partner is the victim. This may explain the narrative of cancer, rape and heart disease operating in these men's lives. The risks are increasing for the HIV positive people. Paradoxically, the risks increase for their sexual partners.

Seen in this way, risk as Castel (1991) argues, is a complex set of abstract factors. However, risk continues to be identified as 'the HIV positive body' and as such is subject to increasing controls and regulations. The risks, however, are managed personally and privately. With the growing number of HIV positive people in New Zealand there is an opportunity to theorise risk as social factors (Castel 1991) and not as an isolated aspect of someone's life. Beck (1992) and Giddens (1990) provide a wide definition of how risk operates in society. This thesis has argued that when risk is identifiable, in this case the HIV positive sexually active man, there is the possibility of increasing risks for both HIV positive and negative people.

Three variables of a sociology of risk (Rhodes 1997) are illuminated in this thesis to highlight the management strategies in place for these men. Firstly, they view risk as a fixed and static thing. Today risk is seen as disclosure, an activity, something to be controlled and largely individualised by the men. They see risk as something they must manage.

[Mandatory disclosure] would make life bloody difficult, deciding if you would. You either refrain from sex or you make sure that you have people that were the sort of people that you could disclose and, or else there could be a back lash, or make sure you were safe and hope like hell no one finds out sort of thing (Ray).

Secondly, disclosure is avoided by not talking about HIV to sexual partners. While some of the men will acknowledge HIV if the subject is introduced the positive men are not introducing the issue. Talking about HIV means for these men that they take a risk in having someone else know the information. This risk is considered too great for most of these men and in practice this is weighed up. Consistent with earlier findings the positive person retains control by not talking about HIV.

I wouldn't tell him for that reason. Obviously if I brought them home I'd be wanting to have some sex. I mean I have needs too and as long as I am careful and protect them and try to do things that are going to protect them as much as I can, obviously I try to expose them to no risk (John).

Thirdly, desire and the process of desiring impacts on how risk is managed by the men. For example, two men move within a fringe milieu of sexual partners. This fringe community is void of safer sex norms and mores; thus the men can be sexually active in this milieu. This is not suggesting that these men deny or minimise the risks of transmission rather, that a complex set of social action results in these men moving within this fringe milieu. Other men desire the sexual satisfaction of their partner, again placing themselves at risk of sexually transmitted infections. Another man desires sex with younger men.

I don't let older men come in my mouth, because I don't want older men coming in my mouth. To me it's a youth thing, to be honest, if a person was going to come in my mouth and I was going to enjoy it, it would be a young person. We seem to get these people turning up who are 15 and three-quarters or 15 and a half or just about to turn 16 but they could actually be 14.

Given the context of non-disclosure, the passive approach to sex, and the age of the sexual partner the risk of transmission seems possible.

The three tensions (of social pressure, living with uncertainty and social closure) occur in social action and are therefore components within a discourse of risk. The literature points to power issues, disclosures, sexual scripts, community connection and seeking pleasure as components within a framework of risk. These aspects of social action for HIV positive men operate within a framework of tensions around disclosure and possible stigma, hostility from the gay community and resistance to parts of the medical community. One possible explanation for this resistance and tension is in relation to a safe-sex discourse.

The discourse of safe sex advocates protection against the dangers of disease thought to be inherent in abandoning oneself to the body of a stranger (Diprose 1998, p1).

In providing protection from a virus already within the men the question can be asked: What impact has safe-sex culture, built on a binary of safe/ unsafe (HIV negative/ HIV positive) had on HIV positive people? The men identify the gay community as the source of hostility toward issues of HIV and, while Shane makes the link between societal homophobia and HIV-phobia, the aspect of social closure by a gay community toward these HIV positive men highlights the use of theorising a sociology of risk. This study shows that those with longer diagnoses are facing the same issues as recently diagnosed people. Only one of the three men diagnosed between 1986 and 1993 will disclose his status and then only in his home inside a relationship. The process of getting to a defined relationship means risk occurs in social action.

The legal opinion of disclosure of HIV status prior to sexual intercourse and oral sex means by not disclosing these men could be charged under the Crimes Act (1961). This legal opinion of the law was published in both *Collective Thinking* (Issue 40, July 1999) and *Express* (8 July 1999). The advice to HIV positive people, as reported, is that positive people must disclose their HIV status and have protected sex with their partners. The advice is that HIV positive people having insertive or receptive anal or vaginal intercourse must disclose their HIV status and use a condom. HIV positive men must disclose their status when they insert their penis in the mouth of their partner (*Collective Thinking* Issue 40, July 1999). There is also advice for women and for people who inject drugs. The advice adds that the legal duties extend to those people who may not know their HIV status but believe they may have been infected.

It is also important to note that while these guidelines relate to sexual behaviour, the same general approach needs to be taken in other situations where risk of transmission exists (*Collective Thinking* Issue 40, July 1999).

In addition to the Crimes Act (1961) the men could be held in effective isolation under the Health Act (1956). Section 92 of this Act states 'every person who knowingly infects any other person with a venereal disease [then] commits an offence' (Paterson 1996, p42). The maximum penalty if convicted is imprisonment of up to one year and/or a fine of up to \$1000 (Paterson 1996, p42). HIV is not covered in this Act, however AIDS was added in 1983. Section 79 of the Health Act (1956) was used in 1999 to isolate two men when 'there was reason to believe or suspect [a person] is likely to cause the spread of any infectious disease' (Paterson 1996, p43). The context of legal interpretation and provisions for effective isolation mean that the HIV positive men may face arrest or isolation for failing to disclose. The impact of this results, as the men state, in them not disclosing. The risk, therefore, is their own arrest. The law is also being used retrospectively. This was highlighted with the case of a fourth man charged this year, under the Crimes Act (1961), for failing to disclose to his ex-partner. An article, under the following headline, appeared in the Christchurch Press on August 14 - *Sex earns jail for HIV-positive man*.

This case, and headline, reinforce the reflexive approach the men in this study have taken toward disclosure and managing stigma. The new risks for them as positive men include arrests for current and historical sex when HIV positive. Christchurch District Court Judge Michael Green, in summing up, is reported to have made the following statement.

Those who contract HIV are going to die much more early than otherwise. Their quality of life will be reduced, and finally full-blown AIDS will kill them off (Christchurch Press August 14).

Beck (1992) theorised that risks, while being an aspect of contemporary life, are often invisible and go undetected. In the case of HIV, as has been argued here, the detection can be made in the body of the HIV positive person. The result of this detection is that risk is seen as self-manageable. Paradoxically, the anxiety that exists



around HIV, Beck would argue, increases the likelihood that the positive person will not disclose. Given recent legal interpretations risks of arrests and retrospective charges may drive HIV underground, producing risk in alternative milieu like the fringe community frequented by Murry and Andrew.

Well legally all I know is that if I have sex with someone and don't use a condom and they contract a virus then I could be had up for manslaughter or grievous bodily harm, that is my understanding. And also apparently if you have unsafe sex and don't tell them and they find out that you had the virus then they can charge you for criminal something but I didn't even know that until this case came up. That's why I am so reluctant to tell people because that information, see this being the law that you have to tell people that is really hard on HIV positive people because it's not that positive people don't want to tell other people (John).

This man captures the tension and risk that exists for him as a sexually active HIV positive man. Being sexually active brings responsibility to the positive person, places them in the situation described above, and in deciding not to disclose they risk future arrest if identified. They risk rejection, isolation and possible violence if they do disclose. The HIV positive men describe a wedge between them and other negative gay men. In light of the context of legal recommendation and increasing surveillance this situation is not surprising.

The increasing pressure placed on the positive men is echoed by the HIV people's group, *Body Positive*, who comment that the new legal opinion

stigmatises the whole thing and makes the HIV positive person 'dirty' - and also it undermines all the work that's been done over the years in New Zealand, to make safe sex the responsibility of both partners...[however] it would be negligent of us not to tell our members [the legal opinion]" (Marshall, cited in *Express* 8 July 1999).

### Developing Inclusivity

A sociology of risk can work within a framework of relational theorising. Such a framework - as developed by Emirbayer (1997) - allows this study to be used in the development of resources for all people, positive and negative, affected by HIV. The men in the Christchurch study see risk as fixed and unitary. Risk is 'a park', 'anal intercourse', and 'the sauna'. Emirbayer (1997, p294) terms this the "engagement by actors of different structural environments [which] both produces and transforms those structures in interactive response to the problems posed by changing historical situations." What is significant about the findings in my study is the unidirectional view these men see their relationships with society to be.

Developing inclusivity for positive and negative men would address Marshall's (cited in *Express*, 1999) concern that the recent legal opinion impacts only on the positive person. This neglects the issue of shared responsibility and reinforces an individualised risk position, something Giddens (1991) would argue is an outcome of the increasing risks for HIV positive people. If safe sex translates into an unachievable goal and results in an internalised experience of failure the men may give up and just accept an alternative sexual experience. However, safer sex can be introduced to provide an alternative to the existing current binary. Safer sex means a continuum of experience. As these men are at differing stages of knowledge, experience, identity and sexual practice, safer sex would, as a concept and in practice, potentially involve each of them. Risk can become individualised and has been shown to be central to how these men view sex while being HIV positive. If risk is reframed as a process, something the men can be involved in as well as something they see themselves at, the issue of sexual safety would be developed as a relational experience and would not make disclosure central to a safer sexual experience for either sexual partner. Being HIV positive means to already have the virus safe sex attempts to restrict. Safer-sex is a continuum allowing risk to be understood as

relational and not fixed. A safe-sex discourse is one premised on a binary: safe/unsafe. A safer sex discourse is one premised on all sexual desire and action.

Community research perspectives and a growing international literature on the effectiveness of community based approaches to HIV/AIDS (Allman et al 1997) may mean more involvement by HIV positive people in producing an inclusive perspective. It is by building strong supportive networks that understanding and support will foster openness and understanding around HIV/AIDS. For disclosure to be effective in New Zealand as a safer-sex strategy these ten men (and others like them) must see a risk reductional frame in the risks they take. This counters the 'safe-sex' frame considered unobtainable by some of the men. Safer-sex education must address the meanings these men attach to their sexual practice (Adam et al 1998).

Safe-sex discourse, it has been argued here, is one constructed around a binary. The very virus these ten men are advised to stay away from (through safe-sex practice) is one that exists within them. This study has illuminated and theorised this experience and found the structures designed to assist those with the virus perpetuate a culture of silence around HIV. The gay community is not open to or accepting of these men because they have HIV. Assumptions made by medical staff invite one man in this study to create an alternative infection story. Risks are taken in attending clinics and stigma may result from disclosure, as one man feared bumping into others he knew. Questions by health staff, coupled with their assumptions regarding transmission, have been identified in this study as issues for the men.

Taking risks is part of our contemporary experience (Giddens 1990). However, reducing risks is also a contemporary coping skill. The men in this study demonstrate skills in terms of managing information, sexual practice knowledge, and a continuum of acceptance of their status. These men are or will be sexually active. How these men continue to manage sexual and social lives can be assisted by a systemic response to their needs. They identify support from peers and family as scant, disclosure as

difficult and sexual practice as different post diagnosis. Their sexual activity exists within a risky framework.

#### Application of the Research: The Christchurch Study

The results from this study indicate that for this group of men the relationship they have with wider society, including gay community, is perceived as one of pressure because they have HIV. This means their responses and experiences are directed by how they view the world around them. How people view risk is dependent on how they view the situation they are in. The literature on life with HIV in New Zealand is only beginning and this study goes some way in developing a sociology of risk in relation to HIV positive people.

Drug treatments are becoming more complex and have side effects for some people. Resistance to medication has been shown with three men stopping treatments. Condoms were also revealed in this study to become metaphors for intimacy barriers, reminders of HIV and in one case a signal of being 'dirty.' Given the complexities in disclosure and associated risks with this the men find reminders of life with HIV ever present.

The Christchurch men live with the virus a safe-sex culture promotes to avoid. Thus, the very culture designed to assist men have enjoyable and safe sex with other men may be closing out the very people it seeks to involve. An alternative, supported by international literature posits a safer-sex discourse of risk-reduction (McClure et al (1999). Such a discourse means safety, like risk, is contextual and can be sociologically considered.

From this research, it can be observed that sexual activity for these men is self-negotiated; that is, self-talk exists and actions are determined without the negotiation of a partner. Furthermore the activity engaged in is managed around avoidance

strategies. This activity decision base is conscious and considered as a factor in life with HIV. However, as the men have reported, sexual practice is pressured for HIV positive people in terms of disclosure and potentially stigmatising outcomes. Therefore this tension, between not talking (thus remaining outside of the sexual partnership) coupled with meeting the sexual needs of the other operates at a level taken for granted by the men. What this may mean is that in managing a non-disclosure sexual experience the sexual needs of the other remain dominant over the HIV positive man's needs.

Disclosure of one's HIV status before sexual intercourse, protected or unprotected, and in certain acts of oral sex is recommended by the New Zealand AIDS Foundation (*Collective Thinking*, 1999). Placing the responsibility onto HIV positive people in this way, Beck (1992) would argue, supports the thesis that risk is further individualised. My research has shown that the reality for these men is that they are unable to disclose, the risks are too great. As one man comments, society has to be open to HIV positive people being sexually active.

Well if it was, perhaps safe sex would be quite easy for most people. They wouldn't feel the need, they wouldn't have to feel that, that, if they told someone, that person was educated enough about the situation, it wouldn't matter (Bruce).

Society, this man argues, must be prepared to welcome disclosures. Without addressing societal issues, in terms of the comfort for others around HIV, the positive men here remain managing the risks as they see them. As previously discussed, a history of disclosure experience will frame how an HIV positive person approaches disclosure.

This approach is coupled with the knowledge that disclosure may mean rejection, violence, isolation and possibly an arrest. Green (1995) reports that HIV positive people who remain celibate have a nil transmission risk of HIV yet high psychological

stress. Green's (1995) study also reveals that those HIV positive people who manage behavioural change develops a lower transmission risk and a lower experience of stress. However, those people who deny their status to themselves or others, and this may include non-disclosure, have a higher transmission risk yet lower associated stress. The Christchurch study is consistent with Green's findings in that those men who are currently not sexually active desire a longer-term partner, in some cases another HIV positive person. If these men manage behaviour change (that is, to develop an eroticised safer sex base) they will be at a lower transmission risk level and have lower associated stress. The Christchurch men who do not disclose to sexual partners yet employ a series of skill based actions to determine risk are managing stress, in terms of HIV infectivity, and distancing in terms of trust in their partners. This additional pressure, Green (1995) would argue, leaves these men in higher risk situations in their sexual lives.

The Christchurch study is consistent with the literature that shows life with HIV is not becoming any easier for those infected. The social aspects of life with HIV are providing new challenges for the person with the virus. Providing a framework of support consistent with social and legal policy can work to become a cohesive and inclusionary framework for sexual health. These men see themselves 'outside' of the local gay community. This community developed a response and support structure around HIV issues in a time before the virus was identified (Lindberg et al 1996). Life with HIV is a complex and dynamic experience today. The experience and management of the issues require skills these men demonstrate. However, there is an identified subjection of the positive men by a system originally defined as assisting them. This tension in determining what support there may be relies on aspects of disclosure. A narrative structure is developed in the management of an HIV positive life.

Making sense of life as HIV positive is premised on the tensions identified in this research, for these men. As the tensions are managed by the men so too is risk.

Dominant epidemiological frameworks of risk are part of popular culture and central to the prevention discourse. Such a perspective focuses on the virus and physiological aspects of health. Social research captures the experiences of these men's lives. As such, the meanings these men give to anal sex, negotiation, intimacy and desire can be considered and the risks associated with these aspects of the men's lives included into an analysis of our society. Beck (1992) and Giddens (1990) provide a framework that has been used here to do this.

All men reside in Christchurch, a regional city in New Zealand. As discussed previously, the men were diagnosed between 1986 and 1997 and provide a range of experiences of life with HIV in 1999. Most of the men in this study expressed concerns around money and their financial situation. Living with uncertainty, social closure and societal pressures highlights the complexity of life with HIV for these men, in New Zealand in 1999. There are additional challenges for these positive men. These include treatment choices, technological monitoring, disclosure issues, and sexual negotiation. Regaining power and control was evidenced through a decision to cease drug treatments. The three men who actively addressed treatments as a source of HIV reminder or life dissatisfaction resisted medical advice.

#### Further Research

While this research illuminates aspects of the lived experiences of these men there are a number of areas where further research is identified from this study. Firstly, further research into Maori with HIV would add to the available literature. While hui have been held and work undertaken to learn more about cross-cultural aspects of life with HIV (Te Puni Kokori 1994; Broughton 1996) the issue of identity encapsulated within a sexuality framework together with HIV is a complex one. My study identified three men hold whakapapa links to iwi, yet this identity was not primary for them.

Another area of development for further study would be qualitative research in HIV negative men in New Zealand who have sex with men. In contrasting the two groups, positive and negative, recurrent themes and, perhaps a definition of inclusive educational resources may occur. As the gay community was identified from this study as a site of hostility toward HIV research could be undertaken with members of gay community to consider this hostility. Educational material can be developed in response to the findings. Similarly, repeating this research in another centre in New Zealand, with other positive men, will allow comparisons to these results. Christchurch is a city with significant ethnic difference to Auckland, New Zealand's largest city.

One gap identified in this study is that of the meaning attached to love, held by these men. While only one man was in a relationship at the time of the study more research into the meanings HIV positive men attach to love may assist in developing the findings from this study. Desire and the process of sexualising this was borne out by the men in their approach to sexual activity. Locating the meanings HIV positive men attach to love may further enlighten how risk is negotiated through sex.

Social workers, practice nurses, counsellors, doctors and community workers assist people living with HIV. It is through a practice based research culture that education and awareness will be raised around this dynamic and changing issue. The life history method (Plummer 1983; Dowsett 1996a) has been used to illuminate the experiences of people and can add to this research.

These ten men are at risk in their sexual and social lives. The risks exist within a number of tensions around disclosure and management of HIV status, choices within a medical system and within an often-hostile gay community. This study indicates how these HIV positive men manage partial disclosure while overwhelmingly not verbally disclosing their HIV status. Further research may consider how positive people relate to the safe-sex discourse and, thus, how this discourse could be



reworked to become an inclusive aspect of sexual and social negotiation for negative and positive people.

### Conclusion

This chapter has discussed the findings of the study and identified further opportunities to add to this work. This research has shown that life with HIV for these men is a complex interplay of risk management. Beck (1992) and Giddens (1990; 1991) provide a sociology of risk framework through which the sexual and social experiences of these ten positive men have been viewed. Both Beck (1992) and Giddens (1990) argue risk is a feature of our modern age. As such technological advancements produce ever-increasing risks. Risks today are global, often large in scale and can go unaccountable (Beck 1992). I have argued that when the risk is identified, in this case the sexually active HIV positive man, increasing regulation and surveillance of that body emerges.

This thesis began by situating the lives of ten HIV positive men in a local context of contemporary New Zealand. Neo-liberalism coupled with increasing globalisation results in an individualised, self-responsible focus. This is evident in the health sector as we are encouraged to monitor lifestyle factors, for example diets, drugs and alcohol. The argument here is that self-monitoring an HIV positive body includes reflexivity and this reflexivity impacts on how the men manage the associated risks in their sexual and social lives. The changing relationships these men have with social institutions highlights the daily risks these men manage. New risks have emerged for these men with bio-technological advancements in medication. The risks associated with drug resistance and compliance highlight this (Mellors 1998).

External controls increase to manage the anxiety in our society around HIV. This year the Crimes Act (1991) and the Health Act (1956) were used to detain HIV positive

sexually active men who failed to advise their partner that they were HIV positive, prior to unprotected intercourse. These partners are both current and historic. New legal advice disseminated from the New Zealand AIDS Foundation encourages disclosure and protected sexual intercourse for all HIV positive people. Paradoxically, an increase in regulation over the HIV positive sexually active body produces new risk for their sexual partner and themselves. These ten men do not disclose their status to casual sexual partners. Some men told me they will disclose when they trust their partner. Other research has shown risk can paradoxically increase within long term relationships (Worth et al 1997b).

The findings in this thesis show that these ten men live in a time of tension. Social closure, social pressure and living with uncertainty are features for them. Regulations on disclosure and the management of a range of new risks mean alternative milieu (in the case of Micheal and Andrew one removed from safe-sex norms) become options. For other men the desire for another HIV positive man reduces the risks of legal remedies for an 'anxious society' (Beck 1992). This thesis has argued that an increasingly individualised society means risk will continue to be placed on the shoulders of the identified locus of risk. HIV is identified within the body of these ten HIV positive men. As such, and in light of the risks they manage in their sexual and social lives, it would appear that disclosures will reduce, and the relationship these men have with the local gay community will be left unaddressed. HIV as an issue is in danger of going underground. As such, further transmissions may continue and the current trend of an increasing number of New Zealanders living with HIV may be left to individually confront the social and sexual issues I have discussed here.

Beck (1992) and Giddens (1990; 1991) posit a sociology of risk as an analysis framework, one that has been used in this thesis to argue that the changing social relationships individuals have with social institutions results in the production of new risks. HIV is a global issue, one that Beck (1992) would argue is not easily visible and is difficult to pinpoint to a point of origin. However, this thesis has argued that

when a point of origin can be identified, in this case the body of the HIV positive sexually active man, there is an increase in society's anxiety, and this results in increases in surveillance and social control. Paradoxically this produces a new set of risks for the HIV positive person to self-manage. An expectation of self-monitoring health and behaviour is consistent with neo-liberal policies in health. Such self-monitoring co-exists with an increase in regulation over the HIV positive body. This increase paradoxically places both positive person and their sexual partners in new situations of risk.

In conclusion, this study has illuminated the sexual and social experiences, within a context of risk, for ten HIV positive men in Christchurch, New Zealand. HIV is a narrative marker and, as this study has shown, produces a range of experiences and responses. The men in this study manage their HIV status in sexual practice. They manage desire as a relational exercise and find meaning through a number of strategies in day to day life. Small exercises of resistance are executed as forms of control over their lives positioned as they see it by societal structures. This study adds to a developing research of HIV positive people's experiences in this country, and extends an international literature into the sociology of risk.

*Postscript*

On November 4 1999, an HIV positive sexually active man was sentenced to nine months in prison, suspended for two years. He was also sentenced to two years isolation from the community. In sentencing this man, Justice Abbott is reported to have said the man conducted his sexual affairs in an irresponsible manner and added,

there would be a greater risk to others if [this man] was jailed  
(Christchurch Press November 5, 1999, p3)

Police and health officials are now reviewing the security in place for the ongoing detention of two HIV positive men. The outcome of this means that public health officials and the police can apply regulations (s79 Health Act 1956 and s145 Crimes Act 1961) to detain the HIV positive individual. Medical Officer of Health, Dr Mel Brieseman, is reported to have noted:

There is quite clear understanding of the law and what needs to be involved now (Christchurch Press, November 6, 1999, p3).

**“[This] case had established a precedent which police and health authorities could follow when dealing with similar cases in future”**  
**Detective Inspector Rob Pope**  
(Christchurch Press, November 6, 1999, p3)

Risk is firmly identified and then isolated, protecting an anxious public; however, this approach neglects the issues for our society outlined in this thesis.

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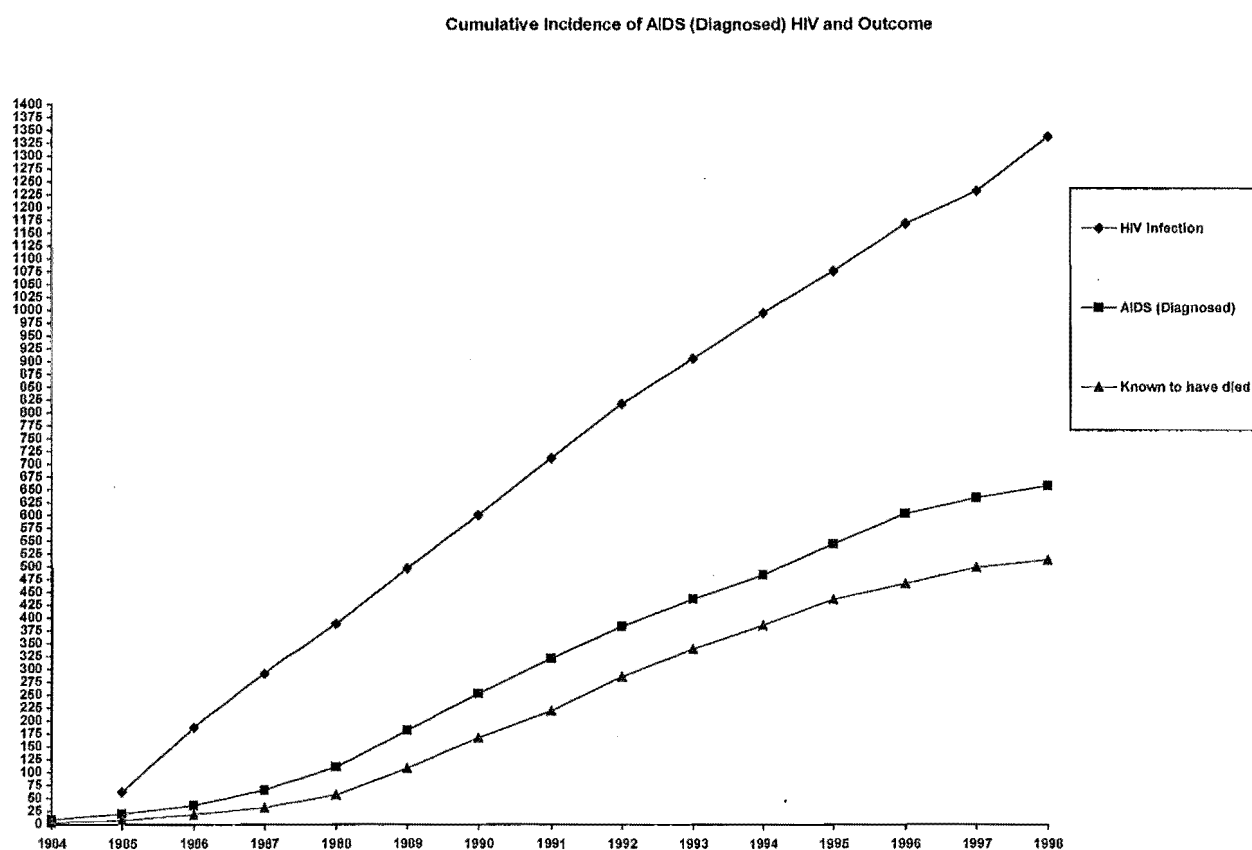
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# Appendix 1

Cumulative Incidence of AIDS (Diagnosed) HIV and Outcome (New Zealand)  
1984-1998 (Source: New Zealand AIDS Foundation)



## **Appendix 2**

### **Brief participant profiles**

#### John

John is an early thirties, gay identifying man with HIV. He sees himself as having a health concern that causes him difficulty in communication and socialising. He does not see HIV as a major issue for his physical health. Currently single, he lives alone, has an income of less than \$10,000 a year and has a history of sex work.

#### Ricky

Ricky is a mid thirties gay identifying man currently living with his partner. Ricky is working full time. He does not consider HIV as causing difficulty in everyday activities people his age do. Earning over \$25,000 a year Ricky is actively involved in the gay community of Christchurch. Ricky's family live in the North Island and he enjoys limited contact with them. Ricky has been HIV positive for 5 years.

#### Warren

Warren is in his mid forties and believes he has lived with HIV from the early 1980s. While jointly owning his home provides him security, he is currently on the Invalid's Benefit. Warren also regards HIV as not having a significant impact on the activities men his age do. He is a gay identifying man and is currently sexually active while not disclosing his HIV status.

Murray

Murray is the oldest participant in this study and is in his mid sixties. Currently renting his home with one other he lives on the Government funded Superannuation Scheme. Murray regards HIV as impacting on his social life more than his physical or mental health. Murray sees himself as a gay man and is currently sexually active.

Shane

Shane is in his early forties and was diagnosed three years ago with HIV. Being gay identified, Shane sees the gay community as an important part of gay life. He rents his home and lives alone. Currently single, he sees a relationship as fundamental to an active sex life. Shane considers HIV as impacting more on communication and socialising than a physical limitation. Currently living on below \$15,000 limits Shane's activities.

Peter

Peter is also a resident of Christchurch, sees himself as a European man and does not speak English. He has a limited social network within the gay community and holds concerns about his HIV status becoming public. Currently renting with one other Peter considers HIV may limit the everyday activities a man in his early thirties could do. Peter supplements an Income Support benefit with part time work. He sees gay and homosexual as one identity.

Bruce

Bruce, early forties, works full time and was diagnosed HIV positive in 1986. He sees no difficulty in the everyday activities someone his age can do. With family in Australia, Bruce sees a supportive friendship network as important. Bruce manages drug treatments and is currently not sexually active.

Alister

Alister is the youngest participant at twenty years old. While identifying as a NZ European/Pakeha, he also identifies as descending from a New Zealand Maori although he holds no formal iwi/ hapu links. He lives on less than \$5000 a year and has dabbled in the sex industry. Alister sees himself as heterosexual and has a history of sex with men and women.

Andrew

In his early thirties Andrew lives alone, rents his home and is unsure how long he has been HIV positive. He has a history of sex with men and women. Andrew does not describe his sexual identity in the conventional definitions but sees his behaviour as the defining aspect. He also has whakapapa links to an iwi he could name, but this is of no importance to him. Andrew dislikes the gay community and keeps much to himself.

Ray

Ray is in his thirties, was diagnosed 5 years ago with HIV and has whakapapa links to an iwi. While identifying as Pakeha Ray sees his Maori heritage as mildly important and may one day seek more information. Currently renting with one other, he is not in a relationship. He sees HIV as primarily impacting on his sexual activity. Earning less than \$10,000 a year limits his social life and he sees himself as having a gay identity.



**Appendix 3a**  
Ethics Committee Approval



**University of Canterbury** Private Bag 4800  
Christchurch New Zealand  
Telephone: 03-366 7001  
Fax: 03-364 2999

1 April 1999

Tony Stanley  
C/o Dr Arnold Parr  
Department of Sociology  
UNIVERSITY OF CANTERBURY

Dear Tony

The Human Ethics Committee advises that your research proposal "**Positive Sex: HIV Positive men talking about social negotiation**" has been considered and approved.

Yours sincerely

A handwritten signature in cursive script, reading "Isobel Phillips".

Isobel Phillips  
*Secretary*

**Appendix 3b**  
Ethics Committee Approval

***Health Funding Authority***

**CANTERBURY ETHICS COMMITTEE**

28 April 1999

Tony Stanley  
Flat 11/144 Stanmore Road  
Christchurch 1

South Office  
4th Floor, 144 Kilmore Street  
PO Box 3877  
CHRISTCHURCH  
New Zealand  
Telephone 03 372 1000  
Facsimile 03 372 1015

Dear Tony

**Positive Sex: HIV Positive Men Who Have Sex With Men Talking about their Social Negotiation**

**Investigators: Tony Stanley Supervisor: Dr A Parr**

**Protocol Number: 99/04/035**


Thank you for your response to the points raised by the Committee. I am pleased to advise that, using the delegated authority granted her by the Committee, the Chairperson of the Canterbury Ethics Committee has given final ethical approval for this study to proceed in Canterbury.

A typographical error was noted in the third paragraph on page 2 where "form" should be "from".

Approvals granted to protocols are for 12 months. If, after 12 months the study is not completed, it will be necessary to forward to the Committee a request for an extension. A form to assist with this is available from the Administrator. Please quote the above protocol number in all correspondence relating to this study.

It is also a requirement of the Committee that researchers submit a report upon completion of their studies. I look forward to receiving your report in due course.

Yours sincerely



Sally Cook  
Ethics Committee Administrator

**Appendix 4****Consent Form**

23 April 1999

**Consent Form****A study in the social relationships of HIV positive men in Christchurch**

Please read the following form carefully and if you are in agreement with the contents please sign in the space provided.

I have read or have had read to me the information sheet dated April 23 1999 for volunteers taking part in the study of HIV positive men in Christchurch. I have had the opportunity to discuss the project and am satisfied with the answers I have been given. I understand that all identifiers of me will be changed in the published research.

I am aware that the interview will be tape-recorded and am satisfied with the storage and destruction of the material collected. I have had time to consider whether to take part and I know whom I can contact if I need further information about this project or my role as a research participant. My participation in this study is confidential and no material that could identify me will be used in any reports from this study. I understand that the project has received ethical approval from the Canterbury Ethics Committee and the Human Ethics Committee at Canterbury University.

My involvement in this research is voluntary (my choice) and I can withdraw from it at any time. This will in no way affect my future relationship with the Ettie Rout Centre, the Christchurch office of The New Zealand AIDS Foundation.

I wish to receive a copy of the summary of the results of the study

(Please circle)      Yes    /    No

**Consent Form (page 2)****A study in the social relationships of HIV positive men in Christchurch**

I \_\_\_\_\_ hereby consent to take part in the research project being undertaken by Tony Stanley from The University of Canterbury.

Signature\_\_\_\_\_

Date\_\_\_\_\_

Contact phone number for researcher:

Project explained by:

\_\_\_\_\_  
Tony Stanley

Date\_\_\_\_\_

**Appendix 5**  
Demographic Form

1. Date of birth

2. Age

3. Ethnicity

New Zealand European or Pakeha

New Zealand Maori

Iwi (if known)

Are you descended from a NZ Maori?

Did you have a Maori grandparent?

Other ethnicity

4. Do you rent your home or own it

5. Do you live with other people?

6. What is the relationship with the other people you live with?

7. Does a health problem, or a condition, cause you difficulty in

Everyday activities that people your age do

Communicating, mixing with others or socialising

Any other activity that people your age can usually do

No difficulty with any of these

8. What is your highest level of your education?
9. Have you trained in any other field?
10. What is your yearly income?
11. Are you currently employed?
12. How many hours each week are you in paid employment?
13. How many hours each week are you in non-paid employment?
14. Where does your family live
15. What is your sexual identification (what do you identify as)
16. What is your sexual orientation (who are you attracted to sexually)
17. What is your sexual behaviour (what do you do sexually)

## Appendix 6

The Christchurch Press  
April 14 1999, p9

# Immigrants with HIV too big a risk - Delamere

by Helen Bain  
in-Christchurch

All prospective immigrants to New Zealand must be HIV tested and refused entry if they test positive, Immigration Minister Tuariki Delamere says.

Mr Delamere said he was preparing a paper to put to the Government proposing that all immigrants, including refugees, be HIV tested in their own countries before coming to New Zealand.

If they tested positive, they should not be allowed into New Zealand because they presented too big a health risk to New Zealanders, Mr Delamere said.

"Some people might say that is cruel and heartless, but tell that to the women infected by Feticus Aids," Mr Delamere said.

At an anti-Aids event, he was killed after infecting a number of New Zealand women with HIV. As well as testing incoming immigrants in New Zealand, HIV positive

immigrants also placed a significant financial burden on the health system, Mr Delamere said.

All refugees who enter New Zealand under the refugee quota programme are given full medical tests on arrival at the Waipapa Detention Resettlement Centre, including a HIV test.

There was no mandatory HIV test but no one had refused one, Mr Delamere said. Also all refugee status claimants were being encouraged to

have free medical tests, Mr Delamere said.

About 4 per cent of refugees tested positive, with 10 to 20 HIV positive immigrants coming into New Zealand each year.

AIDS Foundation executive director Kevin Hague said existing immigrants with HIV was a big problem. Excluding immigrants with HIV would give New Zealanders a false sense of security in leading them to believe the threat of AIDS was being kept out.

Labour immigration spokeswoman Laurie Dargatzis said Mr Delamere's proposal was an unhelpful knee-jerk reaction.

Tuariki Delamere would have learned the hard way that even testing the leaving community she found in New Zealand which she couldn't find in her own country.

"She touched the hearts of New Zealanders, but Mr Delamere would not have had her heart," Ms Dargatzis said.

## Appendix 6

*The Christchurch Press*  
April 29 1999, p1

## Police warn of Chch men with HIV

by Sinead O'Hanlon

Police and health authorities believe two Christchurch men infected with the HIV virus may have had unprotected sex with many people without disclosing their condition.

Gay and bisexual men and women were warned yesterday to seek health advice if they believe they may have had contact with the men. It is not known how many, if any, people may have been infected with the virus through having unprotected sex with the men.

Christopher Ian Truscott, one of the men allegedly involved, has been arrested, the first time a New Zealander has been charged over failing to tell an unprotected partner he carried the HIV virus. The other man, who has been identified by health authorities, remains at large. It is not clear whether he knew about his condition at the time he had sex.

The Canterbury Medical Officer of Health, Dr John Holmes, said the situation was a first for Christchurch and very serious.

Dr Holmes said women and men should be aware of the situation and take appropriate action. He said it would be some time before anyone knew how many people had been infected.

"There is no simple way of knowing whether a person has recently been infected with HIV," he said. "It may take several weeks."

Because of the pending court action against Truscott, authorities will not give any details about the case or say whether either of the men deliberately tried to spread the HIV virus by preying on unsuspecting people.

African musician Peter Mwal died in Uganda last year after serving four years in prison in New Zealand for having unprotected sex with five women while knowing he was infected with the AIDS virus.

Yesterday, Detective Inspector John Doyle said police had reason to believe Truscott was sexually active with other men and was known at homosexual meeting places.

These included North Hagley Park and other places where both openly and covertly gay and bisexual people met for sex, said Mr Doyle. Anyone who has had contact with this man should go to health authorities.

"The people we are concerned about often meet in such a way that they would be unlikely to know each other's names or whether they are HIV positive," said Mr Doyle.

Meanwhile the chief executive of the New Zealand AIDS Foundation, Kevin Hague, said he did not want the situation to develop into a



John Doyle



## Appendix 6

The Christchurch Press May 17 1999, p1

# Police make new arrest for HIV sex

by Kathryn McNeil

Christchurch police have arrested a second HIV-positive man for allegedly having unprotected sex and putting his partners at risk of contracting the virus which leads to AIDS.

The arrest on Saturday follows the arrest of Christopher Ian Truscott, 30, also of Christchurch, who has been in custody since the end of last month. Truscott has entered no plea to a charge of criminal nuisance after allegedly having unprotected sex and not telling his many sexual partners of his condition.

Truscott and the second man arrested will both appear in the Christchurch District Court today.

Truscott has an intellectual disability. The Press understands the second man arrested also has limited capacity to understand and manage his condition, because of a mental illness.

Christchurch AIDS workers would not comment on the second arrest yesterday or on new calls to make HIV notifiable.

AIDS Foundation executive director Kevin Hague said from Wellington that both arrests pointed to failings in the health system.

Everyone had a responsibility to practise safe sex, not just people with HIV, he said. People whose judgment was impaired through disability could not be expected to take full responsibility for themselves and others.

"We'd rather these people were dealt with by the health system," Mr Hague said. "The Health Act provides sweeping powers under which a medical officer of health can require people who put others at risk to be detained in a hospital."

Such powers were originally used to control tuberculosis, but they could also be applied to HIV.

"The Ministry of Health notified all medical officers of health in January that they could use the act in this way with HIV, even though it is not a notifiable disease," Mr Hague said.

The Press understands health officials at the highest level knew long before either arrest that two Christchurch men were indiscriminately

practising unsafe sex. The appropriate Ministry of Health officials could not be reached last night.

A Christchurch AIDS worker who did not want to be named said local health service providers had been involved with both men and had done nothing.

"They have both been very badly let down," he said.

Mr Hague agreed. "These men have diminished responsibilities, and to a large extent are victims of the health system," he said. "They should be getting help, not being arrested."

Canterbury Medical Officer of Health Mel Brieseman is among those calling for more discussion about whether HIV infection should be notifiable, saying a change in its status might improve management of the disease.

Dr Brieseman would not discuss the issue yesterday. He appears to be at odds with other health officials and with AIDS workers who say making HIV notifiable would be a backward step.

If it were notifiable, tracing sexual partners of those diagnosed would be compulsory. It is widely feared that this would deter people from coming forward for testing.

The Ministry of Health senior adviser on public health medicine, Doug Lush,

said there was comparatively little to gain in making HIV notifiable.

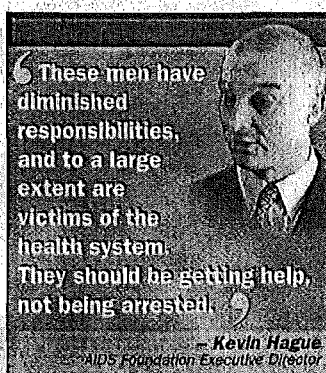
When it became an issue in the 1980s, HIV affected homosexual men, a "highly stigmatised group of people engaged in what was then an illegal activity".

"It was then and is now extremely important that people face no barriers in coming forward for testing," Dr Lush said.

HIV contact tracing was complicated and required the full co-operation of those affected, he said. Under the present system, anyone testing positive was offered counselling, and contact tracing was one of the issues dealt with.

"Most people do act responsibly. In most cases voluntary tracing of sexual contacts does work," he said. "The main issue coming out of this is that people are not practising safe sex."

□ AIDS group slams media, page 6



THE PRESS

## Appendix 6

*The Christchurch Press*  
July 28 1999, p13

## 'Duty' behind HIV publicity

Police had a social duty and obligation to make information about an HIV-positive man public, a constable said in evidence to the Christchurch District Court.

Constable Gary Shaw told the court yesterday the police decided to make certain information public about Christopher Ian Truscott as part of its role in the community and to help make the community safer.

Christopher Ian Truscott, 31, a beneficiary, was committed for trial at the end of a depositions hearing on a charge of causing a criminal nuisance for failing in his duty to tell his sexual partner about his HIV status before having sex with him.

He has pleaded not guilty and was remanded on bail for a pre-trial conference on September 10.

Under cross-examination from Truscott's counsel, Bryan Green, Mr Shaw said the police knew the Christchurch Medical Officer of Health was aware of Truscott's condition when the police decided to go public but held a separate

news conference because the officer wanted to make his own media release.

"We did not know what was in the Medical Officer of Health's release to the public," Mr Shaw said.

Several people had approached the police after the media release but had been apprehensive about becoming involved in a prosecution, Mr Shaw said. None had made a formal complaint.

Mr Shaw said police had an area of Hagley Park under surveillance before Truscott's arrest. The area included changing sheds near a footbridge at the end of Kilmore Street.

Mr Shaw said the area was known to police as a place people went for anonymous sexual encounters, or "beat sex" as it was known.

At least two surveillance operations were carried out, one about a month before Truscott's arrest in April, and another before that but within the last six months.

## Appendix 6

*The Christchurch Press*  
August 14 1999, p2

# Sex earns jail for HIV-positive man

by John Henzell

An HIV-positive man has been sentenced to nine months jail for not telling his girlfriend of his condition while having unprotected sex with her.

Darryl Peter Kilpatrick, 36, unemployed, had feared that telling the truth would have caused the relationship to end.

He only did so after six months when a doctor threatened to tell her himself.

Christchurch District Court Judge Michael Green said that decision had endangered the woman's life.

He said the court had to impose a deterrent sentence to alert others of the importance of their responsibilities to their sexual partners.

"Those who contract HIV are going to die much more early than otherwise. Their quality of life will be reduced, and finally full-blown AIDS will kill them off," he said.

"You have this disease yourself yet you had no problem in having unprotected sexual intercourse with a woman you claimed to love and who, quite plainly, loved you.

"Every time this occurred, there was a very grave risk that she too would become infected with the disease. Having no scruples, you carried on.

"You weren't in denial at all. Your plan was you didn't want to tell. It may well be that you were deflecting her inquiries over a length of time."

Kilpatrick's girlfriend had been shocked by the disclosure, but tests had shown she had not apparently contracted HIV, the judge said. Kilpatrick admitted a charge of criminal nuisance.

Despite Kilpatrick's fears that telling the truth would have ended the relationship, the woman later took him back and recommenced a sexual relationship, albeit using safe sex practices, which lasted until this year, Judge Green said.

Bryan Green, defending, said Kilpatrick had met his girlfriend while he was a psychiatric inpatient at a Wellington hospital suffering from a major depressive episode. He had not been promiscuous.

Of his other two sexual partners since 1993, one was the woman who infected him and the other was told about it before they had sex, counsel said.

**Judge Michael Green**  
Christchurch District Court

**Those who contract HIV are going to die much more early than otherwise. Their quality of life will be reduced, and finally full-blown AIDS will kill them off.**

"There is no suggestion he has placed any other person at risk."

Prosecutor Phil Shamy said Kilpatrick had embarked on a "deliberate course of deception" which ended only at the intervention of a doctor. "He didn't want to lose this woman. His reasons were purely selfish."

● Mr Shamy said the Crown would appeal against last month's sentence on an HIV-positive man who failed to tell his sexual partner before having unprotected sex. Richard Paul Burley, 32, unemployed, was ordered to come up if called upon for sentence in the next 12 months after pleading guilty to a criminal nuisance charge.

## Appendix 6

The Christchurch Press October 23 1999, p1

# HIV carrier 'menace to society' Prostitute admits charge

by John Horzell

Health professionals had known since the late 1980s that male prostitute Christopher Truscott had had sex with thousands of men, often without using protection.

In October 1989, the intellectually handicapped beneficiary was branded a "menace to society" by an Auckland venereologist for his conduct, which risked contracting and then spreading HIV.

Over the next 10 years, Truscott became HIV-positive but continued to work as a male prostitute in Auckland, Wellington, and, since 1997, Christchurch. He also continued to frequent homosexual bars and meeting places.

In December, the Ministry of Health issued advice to the Canterbury Medical Officer of Health that Truscott could be indefinitely detained in isolation under a previously unused section of the Health Act.

When no action had been taken against Truscott by April, the police moved in and arrested him on a charge of criminal nuisance for failing to tell his sexual partners about his HIV status.

In the Christchurch District Court yesterday, Truscott, 31, pleaded guilty to a representative charge of criminal nuisance involving four men.

The charge included an incident in January, after the Ministry of Health had issued its advice, in which Truscott had refused to wear a condom and lied that he was "safe".

Judge Murray Abbott remanded him for sentence next month.

Christchurch Central MP Tim Barnett said police felt compelled to intervene because of the health system's attempts to duck responsibility for detaining Truscott, who he understood had had thousands of sexual partners.

"Nobody was prepared to stick their neck out," he said.

"That delay risked infection for many men. Infection with HIV is life-destroying, expensive, and in some cases will lead to death."

Labour's health manifesto, to be released next week, included a section spurred by Truscott's case and requiring the health system to take responsibility for it, he said.

Aids Foundation executive director Kevin Hague

said the foundation first became aware late last year of claims that Truscott was having promiscuous unprotected sex.

He said it contacted the Ministry of Health, which in December issued advice to the Canterbury Medical Officer of Health, Dr Mel Brieseman, that section 79 of the Health Act could be used to order the isolation of men such as Truscott with infectious diseases.

"Someone who was put at risk, who found out later that the health authorities might have acted earlier and effectively isolated Truscott before that incident, might have some cause for complaint," Mr Hague said.

Dr Brieseman said he received the advice on January 6, after the incident described in court, and said the ministry's statement was only that section 79 "could be considered".

He decided not to invoke the section because his interpretation was that it did not apply to Truscott because he only had HIV, a non-notifiable disease, rather than AIDS.

Instead, he sought a legal opinion from the Ministry of Health to confirm his view.

The ministry later ruled that section 79 could be used but before that had happened, the police had arrested and charged Truscott, who was remanded in jail pending a hearing.

In May, Truscott and another HIV-positive man facing a criminal nuisance charge were given bail on condition that they be kept in isolation under section 79 of the Health Act. They have remained there since.

Inspector John Doyle said HIV was a public health matter but the police were compelled to intervene once it was alleged that Truscott was having promiscuous unprotected sex without disclosing his HIV status to his partners.

"This is a very serious offence and the impact is very, very serious," Mr Doyle said.

"The police would be failing in their duty to the public if they didn't take early action."

He said that three months after the offence in January, section 79 had not been invoked and he understood that there was no facility in which Truscott and the other man could be detained in isolation "with any degree of certainty".



Christopher Truscott